Journey Through the Valley

A Presbyterian Resource for End of Life Issues



"Even though I walk through the darkest valley, I fear no evil; for you are with me..."

Psalm 23: 4 (NRSV)

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Suggestions for Congregations for Observing a Day of Prayer for Healing and Wholeness

The 219th General Assembly (2010) took action on an overture brought by the Presbytery of Upper Ohio Valley urging congregations to set aside a day every year as a day of prayer for healing and wholeness and suggesting

"... that this be done in conjunction with the day currently designated on the Presbyterian Planning Calendar as Health Awareness Sunday. Local churches and communities are encouraged to gather together and offer prayer for the discovery of ever more effective means of treatment. These gatherings may be an occasion to give thanks for the lives of saints who have died; prayers for healing for those who are currently receiving treatment; as well as prayers for doctors, nurses, and scientists who are seeking to bring healing and hope."

Service of Healing and Wholeness

Consider holding a service of healing and wholeness for your congregation. Included in the *Book of Common Worship* are "A Services of Wholeness for Use with a Congregation" (p. 1005) and "A Service of Wholeness for Use with an Individual" (p. 1018).

Suggested Hymns

For Healing and Wholeness:

"O Christ, The Healer" (*The Presbyterian Hymnal*, #380)

"O Savior, In This Quiet Place (*The Presbyterian Hymnal*, #390)

"There is a Balm in Gilead" (The Presbyterian Hymnal, #394)

"You Are Mine" (Sing the Faith, #2218)

"Healer of Our Every III" (Sing the Faith, #2213)

In Celebration of a Life:

"For All the Saints" (The Presbyterian Hymnal, #526)

"Give Thanks for Life" (The Presbyterian Hymnal, #528)

"When We Are Living" (The Presbyterian Hymnal, #400)

Suggestions for Prayer:

The following prayers from the *Book of Common Worship* can guide a time of prayer, both for use by persons in a time of private prayer and for prayer in a service of worship. Other appropriate prayers, as well as sentences of scripture, scripture readings and liturgies can be found in the section "Pastoral Liturgies" (p. 967 and following) in the *Book of Common Worship*.

For healing

Mighty and Merciful God,

you sent Jesus Christ to heal broken lives.

We praise you that today

you send healing in doctors and nurses,

and bless us with technology in medicine.

We claim your promises of wholeness

as we pray for those who are ill in body or mind,

who long for your healing touch.

Make the weak strong,

the sick healthy,

the broken whole,

and confirm those who serve them

as agents of your love.

Then shall all be renewed in vigor

to point to the risen Christ,

who conquered death that we might live eternally. Amen.

-Book of Common Worship, copyright 1993 Westminster/John Knox Press, p. 831.

For healing

By your power, great God,

Our Lord Jesus healed the sick

And gave new hope to the hopeless.

Though we cannot command or possess your power,

We pray for those who want to be healed

(especially for N).

Mend their wounds, soothe fevered brows,

And make broken people whole again.

Help us to welcome every healing as a sign that,

though death is against us,

you are for us,

and have promised renewed and risen life

in Jesus Christ the Lord. Amen.

-The Worshipbook: Services, copyright MCMLXX The Westminster Press. As altered and printed in the Book of Common Worship, copyright 1993 Westminster/John Knox Press, p. 988.

For health restored

Almighty God,

We rejoice that, by the power of your Spirit,

You have given the gift of healing and wholeness

To your servant N.

In thanksgiving we renew our commitment to you,

so that health regained

May provide opportunities for service

in the helping and healing work of Jesus Christ,

our Lord and Savior. Amen.

-Book of Common Worship, copyright 1993 Westminster/John Knox Press, p. 831.

For the sick

Lord of all health,

you are the source of our life

and our fulfillment in death.

Be for N now

comfort in the midst of pain,

strength to transform weakness,

and light to brighten darkness,

through Christ our Lord. Amen.

-Services for Occasions of Pastoral Care, Supplemental Liturgical Resource 6, copyright 1990 Westminster John Knox Press. As altered and printed in the Book of Common Worship, copyright 1993 Westminster/John Knox Press, p. 988.

Prayer of Thanksgiving, Supplication, and Intercession (from "The Funeral: A Service of Witness to the Resurrection")

O God,

before whom generations rise and pass away,

we praise you for all your servants

who, having lived this life in faith,

now live eternally with you.

Especially we thank you for your servant N.,

Whose baptism is now complete in death.

We praise you for the gift of his/her life,

For all in him/her that was good and kind and faithful,

For the grace you gave him/her,

That kindled in *him/her* the love of your dear name,

And enabled *him/her* to serve you faithfully.

Here mention may be made of the person's characteristics or service.

We thank you that for him/her death is past and pain ended,

And that he/she has now entered the joy you have prepared;

Through Jesus Christ our Lord. Amen.

-Book of Common Worship, copyright 1993 Westminster/John Knox Press, p. 921.

Personal Thoughts on End of Life Care

...Decades in the Making...

January 2011

Ruth Syre MSN, RN, FCN

"I come to the end — I am still with you."

Psalm 139: 18 (NRSV)

I have been in and around hospice care since the 1970's. Having grown up as a pastor's daughter, literally living between a funeral home and a cemetery, I was accustomed to talking about illness, dying and death. I dared to take an "avant garde" elective on death and dying as an undergrad, which forced me to begin to look closer at my own attitudes toward end of life issues. My young nursing career took me into neonatology, an area where questions about quality of life were particularly sensitive. At the same time, I befriended pioneers in the area of death and dying, including Elisabeth Kubler-Ross, Joy Ufema, songwriter Deanna Edwards, and others. I thought I was part of a movement that would radically change the way our culture dealt with death and dying. It was the 70s, and the concept of "movement" was alive and well.

Fast forward to current time. My life has been filled with the twists and turns that life will bring. My career has flourished, covering a lot of nursing territory in several states and across multiple specialties. I have worked in and around hospice for most of my career. So, where is the movement of the 1970s? Have we changed in our approach to end of life care?

- We are still reluctant to use the words dying, died, or death.
- Fewer than 30% of Americans have completed an Advance Directive (Pew Research study in 2006), which indicates an avoidance of the issues related to end of life care.
- The mistaken idea of "death panels" was used as a weapon of fear in reference to proposed health care legislation.
- From a Los Angeles Times article, "Choices at the End of Life," Jan. 22, 2010, "The Centers for Medicare and Medicaid Services estimate that 5% of the beneficiaries who die each year take up 30% of the \$446-billion annual Medicare budget. About 80% of that money is spent during the final month, on mechanical ventilators, resuscitation and other aggressive life-sustaining care. Often, the aggressive steps taken to save someone's life are futile. A 2009 study published in the New England Journal of Medicine found that just 18% of adults older than 65 who received cardiopulmonary resuscitation in the hospital survived the procedure long enough to be discharged. In addition, researchers found the procedure in some cases prolonged patients' suffering."

- In a 2009 <u>study of terminally ill cancer patients</u>, researchers at the Dana-Farber Cancer Institute found that, "The patients who leaned the most heavily on their faith were nearly three times more likely to choose and receive more aggressive care near death, such as ventilators or cardiopulmonary resuscitation. They were less likely to have advanced care planning in place, such as do-not-resuscitate orders, living wills, and healthcare proxies.
 - "These results suggest that relying upon religion to cope with terminal cancer may contribute to receiving aggressive medical care near death," the authors write in today's *Journal of the American Medical Association*. "Because aggressive end-of-life cancer care has been associated with poor quality of death . . . intensive end-of-life care might represent a negative outcome for religious copers."
- Anecdotally, my chaplain colleagues share that some oncologists find it extremely difficult to discuss futility of care with patients.
- I know of pastors who have approached chaplains to discourage church members from requesting/accepting DNR status, as this is a mark of "spiritual weakness."

Are there any changes indicating more openness to accepting death as part of life?

- Hospices are flourishing.
- Palliative (comfort) care is becoming more accepted, helping folks transition from the disease-cure to quality of life care.
- Many Faith Community Nurses are open to discussion of end of life care.
- Advance Directives are being promoted, even in faith communities.
- There is a National Health Care Decisions Day (April 16)
- the home or long term facilities, helping EMS staff make decisions during times of crisis. Some states are expanding to "POST"- Physicians Order Set for Treatment, detailing what measures are to be taken for specific situations.
- Health care reform does allow for Medicare consumers and physicians to have discussions around end of life care preferences.
- Organ and tissue donation is more visible, with notification of intent on driver's licenses.

Where could faith communities go from here?

- Advance Directive planning could be included as standard with premarital counseling.
- Seminary curricula could be more intentional in incorporating end of life care issues.
- As people of faith, we may be able to redirect the discussion away from health care dollars to quality of life issues.

We are made in God's image. We are life-affirming. We believe in life eternal. We continue to seek to perceive God's hand on us as we make decisions for ourselves and those we love. The death and dying movement may not have materialized the way I envisioned in the 70s. However, we may move toward a life abundant movement, cherishing the gifts we have, able to surrender to our Creator what we cannot control.

Three Study Guides for Discussing Ethical Issues Raised in 21st Century End-of-Life Care

by Jane Givens, RN, FCN, MAT
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"God is our refuge and strength, a very present help in trouble. Therefore we will not fear."

- Psalm 46: 1

"The Art of Dying Well"

- A. <u>Download the Summer 2006 issues of *HungryHearts*</u>, the PC(USA)'s Quarterly Journal of Reformed Spirituality.
- B. In this issue, various authors reflect on the spiritual significance of death. Articles include reflection questions, prayers, spiritual exercises and thoughtful meditations. A gold mine for anyone preparing a study for adults on death and dying or for personal reflection on this topic.

"What Broke My Father's Heart"

- A. Download the article, "What Broke My Father's Heart"
- B. Invite members of your class or group to read the article ahead of time if possible.
- C. Questions for Discussion:
 - 1. The author tells a little about each of her parents and their philosophies regarding end-of-life issues. Whether you agree with their ideas about death and the way they wanted to die or not, do you think that people have the right to refuse treatment at a certain point? Whose responsibility is it to decide whether to continue treatment?
 - 2. What do you think that the primary care physician's responsibility was in this situation, and do you think he carried his responsibilities out to the best of his ability? What about the cardiologist and his partner?

- 3. Caregivers tend to be spouses who are almost as old (if not sometimes older) as the person for whom they are caring. How could the author's mother have been helped? Do you think that her resentment was typical of most caregivers?
- 4. What (if any) is our responsibility as Christians to recognize that some people (or their relatives) feel that their needs are not addressed as they die? Can we make any kind of difference in changing the way we die?
- 5. What do you feel is the most striking bit of information in this article?

"Letting Go"

- A. Download the article, "Letting Go"
- B. Invite your class or group to read the article ahead of time if possible.
- C. Questions for discussion:
 - 6. The author, Atul Gwande, is a prolific writer regarding ethical considerations of health care practitioners. In this article, he gives numerous examples of his and other doctors' inability to tell a patient or his family that the person has a terminal illness. He says, "In the past few decades, medical science has rendered obsolete centuries of experience, tradition, and language about our mortality, and created a new difficulty for mankind: how to die." After reading this article, do you agree? If so, do you think we should be doing something differently?
 - 7. Because of the way we die now, the customs that Gwande says accompanied dying and death in the 15th century appear to be no more. Do you think customs and dying in the "right frame of mind" are important? Are there customs surrounding death that you remember from your own childhood that you either miss or are glad that are no longer observed? If so, can you name them?
 - 8. What do you think of Gwande's description of doing patient rounds with the hospice nurse, Sarah Creed? When she describes the goal of hospice, is that a new idea for you? Do you agree with her explanation of the difference between standard medical care and hospice? What are your priorities when you die?

- 9. Gwande cites Stephen Jay Gould's essay "The Median Isn't the Message". How do we both prepare for death and treat a disease aggressively? If one prepares for a negative outcome (death), do you believe that one can achieve a more positive outcome (life)?
- 10. "A family meeting is a procedure, and it requires no less skill than performing an operation" quotes Gwande from Dr. Susan Block, a palliative care specialist. If a family meeting needed to be called about your condition, who would you want to be there?
- 11. What do you make of the experiment Aetna did with a group of policyholders who had a life expectancy of less than a year and were allowed to receive both hospice services *and* medical treatments? Given the results, why do you think that we do not do more of this?
- 12. What was the most interesting part of this article for you? Did it change your mind in any way about how death and dying happens in our culture?

Holding On and Letting Go

"I am the resurrection and the life, says the Lord."

John 11: 25

End-of-life decisions are very difficult to make, but are an important part of ensuring that your wishes are respected. This article discusses the instinctive desires people have to continue living, as well as being able to "let go" when faced with end-of-life issues such as chronic illness. Planning ahead will help when the time to make a decision comes. Lastly, the article provides resources about making decisions and exploring hospice.

Click on this link to open the article from the Family Caregiver Alliance website:

http://www.caregiver.org/caregiver/jsp/content_node.jsp?nodeid=400

Advance Preparation for a Christian Memorial Service

by the Rev. Dr. Susan Andrews General Presbyter Hudson River Presbytery

Death is an inescapable part of life. We would all benefit immensely if we were able to accept that fact along with all the other immutable laws of nature, but instead we often avoid, deny, or gloss over its inevitability. Then, when death occurs we are not prepared to deal with that final reality.

Being able to confront and accept the reality of our own death allows us to focus more fully on the quality of our lives here and now. To admit a finite end to this earthly life can most effectively alter priorities. All of a sudden, relationships assume prime importance, time becomes precious, principles of faith are re-examined, values are revised, and all the attributes of mortality are more fully appreciated. These are very real benefits.

To admit the reality of one's own physical death can also allow you to prepare your loved ones for loss. Even young children can learn to accept death if it is presented to them in a caring and factual way, and not cloaked in hushed voices and conspiratorial whispers. It is important to include them in grandparents' and relatives' funerals, and to encourage and allow them to feel sad along with the rest of the family.

It may not be easy for some family members to talk about the death of those they love so deeply, but seeing your acceptance can ultimately facilitate their acceptance as well. It would be very beneficial to find a time to sit down with your family and find out how they feel about everything you are contemplating: e.g., will they concur with your wishes as expressed in a Living Will, how will they feel about organ donations, do they prefer traditional burial or will they be comfortable with cremation, are there any elements they would very much like to have included in your memorial or funeral service? You need to be clear concerning your desires. Although some of your wishes may not exactly coincide with theirs, be sensitive to the fact that they will be the survivors and the ones most in need of comfort.

These are some of the most important reasons for planning ahead. This packet will cover some of the ways to do so.

WITNESS TO THE RESURRECTION UNDERSTANDING A CHRISTIAN MEMORIAL SERVICE

PURPOSE

A Christian funeral or memorial service is a public service of worship, which gives witness to the central understandings of the Christian faith. The purposes are as follows:

- 1. To celebrate the unique gifts of life that God has given us through the person who has died;
- 2. To proclaim the central promises of resurrection that complete the promises of baptism;
- 3. To embrace all the human emotions associated with physical death grief, sadness, loss, anger, guilt, relief, hope;
- 4. To reassure those who are worshipping that "both in life and in death we belong to God," and "that nothing can separate us from the love of God through Christ Jesus our Lord."

THE MESSAGE OF RESURRECTION

The two central teachings of Christianity that separate it from other religions are Incarnation and Resurrection. Incarnation proclaims that the Word became Flesh. God became human in a particular time and place. God came to dwell among us in the person of Jesus Christ so that we might meet and know God, and God's unconditional love, face to face. And then through Resurrection, that unconditional love became a universal power accessible to all, embracing us eternally after our physical death. Resurrection is a promise – a great mystery we cannot "know" but only trust.

The two sacraments, baptism and communion, remind us of this promise throughout our physical lives. At baptism we are incorporated "into Christ." We "put Christ on" through the symbol of water and the promises of the community of faith. Because we are "in Christ," the resurrected Body of Christ, our unique self, or energy, continues to be embraced by that spiritual presence after our physical death. In some churches, the casket is covered with a white funeral pall, the baptismal robe that continues to "clothe" the person who has died. In our sanctuary, the Christ Candle next to the baptismal font is lit during every service of worship, including funerals and memorial services.

In communion, 1) we are fed throughout our lives with symbols of Christ's living presence, 2) we are given a foretaste of the eschatological banquet, when all will be one and reunited, and 3) we are reminded that we share our family meal with the "communion of the saints" who have gone before us.

Traditional scripture texts read during memorial services and funerals remind us of this central and powerful promise of resurrection: I Thessalonians 4, Romans 8, II Corinthians 4, John 14, I Corinthians 15, Psalm 23, and others

PARTS OF THE MEMORIAL SERVICE

- 1. Call to Worship that proclaims the promises of the faith, names the one whose life is being celebrated, and points the worshippers toward God.
- 2. Hymns and special music that underline the celebration of life, the power of the promise, and the victory of God's power of life over the human power of death.
- 3. Scripture passages that embrace the emotional complexity of death, the promises of resurrection, and lift up particular qualities of faith that were embodied in the person who has died.
- 4. Words of Thanksgiving for the one who has died that include memories, stories, and accomplishments. This is most effective when it is done by family, friends, and colleagues of the deceased.
- 5. A pastoral prayer that lifts up the blessings and gifts of the one who has died, acknowledges the pain and loss of death, as well as the mystery of resurrection, that asks God's healing presence in the lives of those who have lost a loved one, and commends unto the Almighty the resurrected spirit of the one who has died a "letting go" into the mystery of God's grace.

As our Presbyterian Directory of Worship suggests, memorial services/funerals are services of worship, giving glory to God. Consequently, reverence, joy, and thanksgiving are the appropriate moods for the service. Garish flowers, secular music, sentimentality, boasting, or excessive emotion can draw attention away from God and can cause unnecessary anguish for those who are grieving.

EMOTIONAL/PSYCHOLOGICAL CONSIDERATIONS

A memorial service/funeral is the beginning, not the ending, of the grieving process. Its purpose is to enable a family to give thanks for the life of the one who has died, to "let go" of the physical remains, and to hear promises of God's love and care that can help in the long difficult process of grieving. It is also a community experience, where a wide range of friends and acquaintances can offer respect and thanksgiving, and can once more come face to face with their own mortality.

PARTICIPATION OF CHILDREN

Quite simply, it is appropriate for children of all ages to be included in the process of death as well as in the celebration of life during a memorial service. It is essential for children aged seven and older to be part of the memorial service of a relative or close family friend. Children of this age have the intellectual and emotional maturity to understand the "finality" of death, and they need the spiritual and emotional resources that the church can provide to help them begin to come to terms with death. If they are left out, they may develop unhealthy fears or superstitions about death and may feel that they are being excluded from an important family time because they did something wrong. To see adults cry and mourn is important. To have their parents share feelings, doubts, and memories openly and honestly can encourage children to be honest about their own feelings. Generally speaking, children

Health Awareness Sunday 2011

handle death more easily than adults, and their presence and resilience can be very healing for the older people around them.

Susan Andrews was Moderator of the 215th General Assembly (2003), Presbyterian Church (U.S.A.) This article was written for Bradley Hills Presbyterian Church, Bethesda, Maryland, March 1997.

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Reflections Before You Visit

"Blessed are those who mourn, for they will be comforted." Matthew 5: 4

Death is a mysterious journey for all of us. It can seem like a lonely, difficult time for those who know that their death or the death of a loved one is drawing near. However, there are people like you standing by, ready to walk this journey with them. Many people in this situation need and welcome persons who do not close off conversations about living and dying. As one who is walking alongside a family during this time, it is good to encourage them to talk and to listen supportively. It may be painful, but it can also bring great joy and a sense of inner peace. Those who know they are going to die soon may want to focus their energy on what is really important and we can help them reflect upon questions like the ones below.

But before the time you might be called upon to offer ministry to a family, it is important for you to ponder on how you might answer these questions about your own living and dying:

QUESTIONS ABOUT LIVING

- What do you still want to accomplish?
- What do you need to do to get your affairs in order?
- Who are the people you want to spend time with?
- Are there letters you want to write, conversations you'd like to have, matters you need to resolve?
- What will bring pleasure to this part of your life?

QUESTIONS ABOUT DYING

- What do I believe about what happens to a person during and after death?
- Are there ways to prepare spiritually for dying?
- What will make me less sad or afraid?
- How do I sum up my life, make peace with who I have been and who I am?

-	What kind of funeral, memorial service, or other remembrance do I want after my
	death?

- Who do I want with me when I die?

For Pastors, Parish Nurses, and Families

What about the Children? An Article and Book List

"Let the little children come to me, and do not stop them; for it is to such as these that the kingdom of heaven belongs. And he laid his hands on them and went on his way."

Matthew 19: 14-15

What Do I Tell the Children?

By Paula Rauch and Robert Arnold

The dying of a young adult is always difficult, even more so when there are young children survivors. A common question asked by the dying adult or their family member is, "what/how do I tell the children". Physicians and other health care providers can provide leadership and guidance to help young families through this crisis.

Screening and Awareness

- Ask if the ill person has children at home;
- Ask about their age, personality, and coping style;
- Ask what the ill person has told the children about the illness;
- Ask if they have a specific worry about the child;
- Ask if the child has had recent problems in school, at home or with relationships;
- Ask who they would like to talk to if they have concerns?

Give them some words.

Often a parent's biggest worry is what to say if the child asks if he or she is dying. Here are two examples of words a parent might use. Asking a parent if these words would feel comfortable to say can begin a dialogue between patient and clinician to arrive at language that is honest, and life affirming.

"X" can kill people, but I am taking the best care of myself I can. I am following the doctor's plan so that I can live as long as possible."

"Even with trying my hardest and getting the best possible care, my _____ is getting worse; still I plan to live every day."

- III. Give adults concrete examples to guide their interactions.
 - 1. Express interest in the child's day.
 - 2. Work to maintain normal routines (e.g. maintain family rituals: Friday night supper, Monday night pizza, watching *Jeopardy* together).
 - 3. Welcome all questions but do not force discussions. Make sure you understand the real question before answering; take your time to think about how you want to answer.

- 4. Overhearing bad news is the worst way to hear it. Talk with children from diagnosis onward, being sure to give updates when there are changes in prognosis or treatment.
- 5. Avoid euphemisms (e.g. lump, boo-boo or sickness) that may confuse children.
- 6. Ask children to share what they are thinking or hear from others, so they do not worry alone.
- 7. Prepare children for visits with the sick person. Describe what they are likely to see. Bring along another adult who is comfortable to stay only as long as the child wants. Bring along markers and paper so children can leave the parent with a picture or message.
- 8. Talk to the child's teacher or guidance counselor to alert the teachers. Ask teachers and the child's friends' parents to let the parent know if the child talks about worries.

IV. Refer adults to one of the popular books on the subject (such as those by Kroen or McCue, listed below).

- V. Know the resources for parents and children in your hospital and community.
- VI. Consider referral to a mental health professional when:
 - 1. There are symptoms of depression, or anxiety that interfere with school, home or with peers;
 - 2. There is risk taking behavior;
 - 3. There is significant discord between the child and the surviving parent;
 - 4. There is significant discord between the parents; or
 - 5. The child says he or she wants to talk to someone outside of the family.

References:

Rauch, P. (2000). Comment: Supporting the Child within the Family. The Journal of Clinical Ethics 2000; 11: 169-170.

Harpham, W. (1997). When a Parent Has Cancer. A Guide to Caring for Your Children, HarperCollins.

Keeley, D. Telling children About a Parent's Cancer. BMJ 2000, 321:462-463.

Krementz, Jill. How It Feels When a Parent Dies. Alfred Knopf.

Kroen, W.C. (1996). Helping Children Cope with the Loss of a Loved One. Minneapolis, MN, Free Spirit Publishing, Inc.

McCue, K. (1994). How to Help Children Through a Parent's Serious Illness. New York, St. Martins Griffin.

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Books for Children About Death

- **Grandad's Prayers of the Earth** by Douglas Wood. 1999, Candlewick Press, Cambridge MA.
- I'll Always Love You by Hans Wilhelm, 1985. Crown Publishers, Inc., New York.
- The Legend of the Bluebonnet by Tomie DePaola. 1983, Penguin Books for Young Readers, New York.
- **The Tenth Good Thing About Barney** by Judith Viorst. 1971, Aladdin Books, McMillan Publishing Company, New York.
- Water Bugs and Dragonflies, Explaining Death to Young Children by Doris Stickney. 1982, The Pilgrim Press, Cleveland OH.
- A Child Remembers by Enid Samuel-Traisman, MSW. 2008, A Centering Corporation Resource. A write-in memory book for bereaved children, ages 8-12. This is a unique tool for children who are grieving the death and loss of someone they love. There are pages for writing about the person's life and death, a goodbye letter, pages to draw the service and more. \$6.95. Order online at

http://www.centering.org/index.php?page=book&id=110&pid=515

Helping Your Bereaved Friend

By Helen Fitzgerald, CT

You have a good friend who has just experienced the death of a loved one. Perhaps you know instinctively what to do, but maybe you do not. Perhaps you have never lost a person you love. Maybe you haven't even been to a funeral. This is not unusual. Many people do not have occasion to attend a funeral until late in adulthood. Maybe your friend is of a different culture and you are not sure what rituals or customs would be correct. Use the following as a guide in preparing for the day when a friend has lost a loved one.

Preparing Yourself

You can do some things now to prepare yourself for a future event:

- Review a personal grief experience. Think back to your childhood and to a time you experienced the death of a loved one or even a pet. Remember what it was like for you. Who died? How did you feel? What was helpful? And what was not helpful? The more you understand your personal experience with death and grief, the more comfortable you can be in reaching out to a friend.
- **Become familiar with the process of grief.** There are many books in libraries and bookstores that are written about grief and loss. Find one and read it to understand better what your friend may be experiencing.
- **Use the correct language.** If someone has died, say the word "died" instead of euphemisms, such as "passed."
- Pace yourself. Helping a bereaved friend is hard work, and your friend will need you for months to come. Think realistically about how much time you can give without denying your own family of important time together. In the beginning, your friend will need you more, with less assistance required as he or she becomes more independent.

When Death Occurs

There is so much to do after a death, but ordinary, practical help is needed first.

Practical Help

- Make phone calls and answer the telephone, keeping a record of messages. Make sure the house is presentable, and help to clean it, if necessary. Keep track of food and other gifts for thank you notes, and note which bowls belong to whom for later return.
- **Help with the children.** Children have special needs and may be ignored during this time. Talk to them about what they are feeling and thinking.

- **Run errands.** There are usually dozens of errands that need to be done. Ask for a list or help prepare one. Perform the ones you can and delegate the others.
- **Pick up out-of-town friends and relatives.** Offer to make trips to the airport or bus station to pick up those who are arriving to attend the funeral. Help find convenient and affordable lodging, or make arrangements with neighbors or friends to offer spare bedrooms.
- Encourage your friend to take time out to rest. Grief is exhausting, but if your bereaved friend is running on adrenaline, he or she may not be aware of the body's need to take a break.
- **Help with funeral arrangements.** At the time of death, families are tempted to spend huge amounts of money for the funeral, but their decisions may not be well thought through. Offer to go with your friend to the funeral home, but have a discussion about price beforehand. Spending thousands of dollars is not necessary for a nice funeral. Help your friend make the funeral more personal by incorporating the deceased's personality into a service of celebration of that person's life. If there are children present, suggest a special funeral service that would be shorter and more informal than the adult service.

Emotional Help

- Think about how much time you can give. Before committing yourself, determine how much time you can give without creating problems in your own family. Visits over a longer period of time are more important than many visits during the first week, when other friends and relatives are still available. With the departure of these people, the bereaved may feel isolated. Now is the time for you to start your visits, which may vary in length.
- Learn good communication skills. It is easy to do all of the talking, especially if you are anxious. Try not to fill every pause with chatter unless you have something important to say. Communication isn't always with words; use your eyes, as well. How does your friend look? Is she restless? Has his posture changed?
- **Be a good listener.** Listening is the most important gift you can offer a grieving person. Every time your bereaved friend tells his or her story, the reality of what has happened will sink in. The loss must become real in order for your friend to move through the process of grief. As a listener, encourage your friend to talk and express feelings.
- Help your friend organize his or her day. People tend to feel overwhelmed when a loved has died because there is so much to do. Help organize urgent tasks, and those that can wait until a later time. Develop and post a list that can be checked off when tasks are completed.

- Help with thank-you notes. With an outpouring of support from family, friends and co-workers, this task may seem monumental. Your friend will have certain people to whom he or she will want to write personal notes. However, there are many thank-you notes that can be signed on behalf of your friend. That intimidating pile of cards can decrease quickly with your help.
- Watch the children and their emotional needs. Grief is so encompassing that children may be forgotten or ignored. See to their needs.
- **Share memories.** Sharing memories is so healing. Bereaved people love to hear stories about their loved ones.
- **Watch for depression.** It is normal for bereaved people to experience some depression, and reminiscing usually helps break it up. However, if you feel concerned about the degree of depression your friend may be exhibiting, suggest seeking professional help.
- **Identify local resources.** Find further resources for your friend, such as support groups, books, or therapists who specialize in grief. You can locate resources by calling your local hospice or mental health center.
- Take care of yourself. Helping the bereaved is hard work. Don't
 forget to take care of yourself. Find someone you can talk to. Check
 with your family and remain aware of their needs. Take time for
 yourself to do something special, such as taking long walks, reading
 a book, watching a favorite TV program, enjoying a quiet bath or
 listening to some of your favorite music. Take care of yourself. Your
 friend will need you for a long time.

Avoid Vacuous Platitudes

People sometimes worry that they will say the wrong thing. The following are some things to avoid:

- "I know how you feel." One can never know how another may feel. You could, instead, ask your friend to tell you how he or she feels.
- "It's part of God's plan." This phrase can make people angry and they often respond with, "What plan? Nobody told me about any plan."
- "Look at what you have to be thankful for." They know they have things to be thankful for, but right now they are not important.
- "Call if you need anything." They aren't going to call. It is much better to offer something concrete, such as: "I have two free hours and I want to come over and vacuum your house or work on your lawn."

- "He's in a better place now" The bereaved may or may not believe this. Keep your beliefs to yourself unless asked.
- "This is behind you now; it's time to get on with your life."

 Sometimes the bereaved are resistant to getting on with because they feel this means "forgetting" their loved one. In addition, moving on is easier said than done. Grief has a mind of its own and works at its own pace.
- Statements that begin with "You should" or "You will." These statements are too directive. Instead you could begin your comments with: "Have you thought about. . ." or "You might. . ."
- Making decisions for your friend. You can help your friend make decisions by exploring the pros and cons of what or what not to do. If you make a decision and it ends up being a bad one, your friend may be very angry with you. Moreover, you may be reinforcing dependence on you.
- **Discouraging expressions of grief.** It is best to "encourage" your friend to express grief. If your friends begins to cry, do not change the subject, rather, give a hug, make a pot of coffee or find the tissue.
- **Promoting your own values and beliefs.** Listen to your friend talk about his or her values and beliefs. It's okay to share yours as long as you are not trying to convince your friend that your way is better.
- **Encouraging dependence.** The bereaved may tend to lean on you too much. It is better to gently encourage independence with your support and guidance.

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Helen Fitzgerald is a Certified Thanatologist, author and lecturer. Her books include <u>The Grieving</u> <u>Child: A Parents' Guide</u>, <u>The Mourning Handbook</u> and <u>The Grieving Teen</u>. She has appeared on the CBS Morning Show and the NBC Today Show and was previously the director of training for the American Hospice Foundation. You can ask Helen a question about dealing with grief and loss by visiting <u>Ask Helen</u> on the American Hospice Foundation website. This article is reprinted with permission.

Please, Dear Friend

By Mary Bailey

Please, Dear Friend,
Don't say to me the old clichés,
"Time heals all wounds."
"God only gives you as much as you can bear."
"Life is for the living ..."

Just say the thoughts of your heart.

"I'm sorry."
"I love you."
"I'm here."
"I care."

Hug me and squeeze my hand. I need your warmth and strength.

Please don't drop your eyes when I am near. I feel so rejected now by God and people.

Just look into my eyes, and let me know that you are with me.

Don't think you must always be strong for me.

It's OK to cry.

It tells me how much you care.

Let me cry, too.

It's so lonely to always cry alone.

Please keep coming by
Even after many weeks have passed.
When the numbness wears off,
And the pain of grief is unbearable.

Don't ever expect me to be quite the same. How can I be when part of my being is here no more?

Please know, dear friend,
With your love, support and understanding,
I will live again
And be grateful every day that I have you

Some Resources for Congregational Care and Education about End of Life Issues

Aging With Dignity — "Living will with a heart and soul," educational materials

A national non-profit organization with a mission to affirm and safeguard the human dignity of individuals as they age and to promote better care for those near the end of life. Introduced **Five Wishes**, America's most popular living will, in Florida in 1997, and a year later, to the nation. Dubbed "the living will with a heart and soul," it meets the legal requirements in 42 states and has helped literally millions of people plan for and receive the kind of care they want. *Five Wishes* is unique among all other advance directives and living wills because it is user-friendly and easy to complete. The document is available in 26 languages and in Braille. A presenter's guide, **Sharing the Gift**, is also available. **Next Steps**, a guide to discussing and coping with serious illness, is a companion to *Five Wishes*. The guide includes information on completing *Five Wishes*, talking to family members about completing a living will and discussing *Five Wishes* with your doctor. Included are exact words and phrases you can use to start these conversations. There's also useful guidance on serving as a health care agent and being at the bedside of someone who is seriously ill. The guide contains valuable information and assistance in starting, completing and following up on discussions about end-of-life care. See the website to order materials:

Web address: www.agingwithdignity.org

Mailing Address: PO Box 1661, Tallahassee, FL 32302-1661

Phone: (850) 681-2010 ext. 104

Gloria Keeney, Director of Outreach

Email: g.keeney@agingwithdignity.org

American Hospice Foundation—Resources, educational information about end-of-life care

Web address: http://www.americanhospice.org/

Mailing address: 2120 L Street, NW, Suite 200, Washington, DC 20037

Phone: (202) 223-0204 or Toll Free: (800) 347-1413

Email: ahf@americanhospice.org

Care Notes, Elf-Help — Great little booklets to help you help others

Web address: www.onecaringplace.com

Mailing address: One Caring Place,

Health Awareness Sunday 2011

One Hill Drive, Customer Service Plant 1

St. Meinrad, IN 47577

Toll-free phone: (800) 325-2511

Center for Loss and Life Transition — education and resources

Alan D. Wolfelt, Ph.D., C.T. noted author, educator and grief counselor serves as Director of the Center for Loss and Life Transition and is on the faculty at the University of Colorado Medical School's Department of Family Medicine. Dr. Wolfelt is an educational consultant to hospices, hospitals, schools, universities, funeral homes and a variety of community agencies across North America. Perhaps best known for his model of "companioning" versus treating the bereaved, Alan is committed to helping people mourn well so they can live well and love well. Dr. Wolfelt writes the "Children and Grief" column for *Bereavement* magazine.

Web address: <u>www.centerforloss.com</u>

Mailing address: 3735 Broken Bow Road, Fort Collins, CO 80526

Phone: (970) 226-6050

Email: wolfelt@centerforloss.com

Centering Corporation is a non-profit 501(C)3 organization dedicated to providing education on grief and loss for professionals and the families they serve. The Centering Corporation was founded in 1977 by Joy and Dr. Marvin Johnson. At that time they developed nine coloring books for hospitalized children and two workshop offerings for nurses and families. Over time, this evolved into what is now called Patient Education. Centering Corporation now provides a compilation of over 500 resources for grief and loss including the magazine *Grief Digest*. It continues to provide educational offerings, bookstores, and workshops for caregivers and families, with a heritage of becoming the largest provider of resources for grief and loss in the nation.

Web address: http://www.centering.org

Mailing address: 7230 Maple St.

Omaha, NE 68134

Phone: (402) 553-1200 or Toll-free: (866) 218-0101

Compassionate Friends — for help when a child dies

Web address: www.compassionatefriends.org

Mailing address: National Office, PO Box 3696, Oak Brook, IL 60522

Phone: (630) 990-0010 or Toll-free: (877) 969-0010

Email: <u>nationaloffice@compassionatefriends.org</u>

George Washington Institute for Spirituality and Health (GWISH) — simple, online spiritual history tool that can be downloaded. Current research on spirituality and health.

During the past 20 years, there have been significant advances in medical science in understanding the role that spirituality and religion play in health and well-being. Numerous studies have demonstrated that religious and spiritual beliefs and practices are important for patients coping with illness and stress, in resiliency, and in some, healthcare outcomes. Ethical mandates in all healthcare professions support the integration of spirituality into the care of patients. And because of the importance of spirituality for high-quality, competent, and safe healthcare, The Joint Commission requires that spiritual care be available to patients in hospital settings. Look for their simple **FICA Spiritual History Tool,** a great help to parish nurses and pastors.

Web address: http://www.gwish.org/

Mailing Address: Warwick Building, #313, 2300 K Street NW, Washington, DC 20037

Phone: (202) 994-6228 Email: <u>caring@gwish.org</u>

Healing Liturgies for the Seasons of Life by Abigail Evans, 2004, Westminster John Knox Press. The Product Description reads in part, "Abigail Evans, a leading specialist in bioethics and health ministries, explores how God's gift of healing is available during all seasons of a person's life and how the power of hope and healing are affirmed and redirected through liturgical services, sacraments, and rites. This distinctive resource features specific healing liturgies for injury, illness, death, separation, retirement, and a host of other major life events, from a wide variety of religious traditions." May purchase <u>online</u> or by phone, toll-free: (800) 524-2612 and reference Item # 9780664224820. Also available through Amazon.com, Target, Barnes & Noble, nextag.com, others.

In Life and in Death We Belong to God; Euthanasia, Assisted Suicide, and End-of-Life

Issues 1995 twelve session Study Guide prepared by the Offices of Theology and Worship as directed by the 202nd General Assembly (1990) of the Presbyterian Church (U.S.A.). Each of the 12 sessions includes goals, a list of resources, suggested Scripture readings, a summary statement of basic theological issues, questions for group discussion, suggested prayers, suggestions for group process. Downloadable at no charge:

http://www.PC(USA).org/media/uploads/theologyandworship/pdfs/inlifeanddeath.pdf

Journey of Hearts: An Online Healing Place for Anyone Who Is Grieving

resources and support to help those in the grief process following a loss or a significant life change

Web address: http://www.journeyofhearts.org/

Mothers Against Drunk Driving (MADD) — They provide "a wide selection of brochures for crash victims, available in English and Spanish, covering grief and healing, talking to children and teens about death, coping with serious injury, the criminal and civil court system, and other topics of interest." Your nearest local chapter of MADD can be located on their web site or by phoning their national office.

Web address: http://www.madd.org/

Mailing address: 511 E. John Carpenter Freeway, Suite 700, Irving, TX 75062

Phone: (800) GET-MADD or (800) 438-6233

National Hospice and Palliative Care Organization — most up-to-date information available. Advocates for the needs of people facing life-limiting illness. Offers free resources on a variety of end-of-life issues to people via our Caring Connections Web site and HelpLine.

Web address: http://www.nhpco.org

Mailing address: 1731 King St., Ste. 100, Alexandria, Virginia 22314

Phone: (703) 837-1500

Email: nhpco.org

National Sudden and Unexpected Infant/Child Death & Pregnancy Loss Resource

Center— The National Sudden and Unexpected Infant/Child Death and Pregnancy Loss Resource Center at Georgetown University serves as a gateway to critical information on risk reduction, prevention, and bereavement for sudden unexpected infant/child death and pregnancy loss, including sudden infant death syndrome, miscarriage, stillbirth.

Web address: http://www.sidscenter.org/

Mailing address: 2115 Wisconsin Avenue, NW, Suite 601, Washington, DC 20007

Phone: (202) 687-7466 or Toll-Free: (866) 866-7437

Email: info@sidscenter.org

Bilingual grief counseling (English & Spanish) available 24 hours a day, 7 days a week: (800)

221-7437

Praying Our Goodbyes: A Spiritual Companion Through Life's Losses and Sorrows by Joyce Rupp, 2009, Ave Maria Press. Probing questions at the end of each chapter. 24 prayer experiences that would be valuable to families, pastors and parish nurses. Order from <u>Ave Maria Press</u>, <u>Amazon, Barnes & Noble, Borders</u>.

SHARE—Pregnancy and Infant Loss Support Inc. — serves those whose lives have been touched by the tragic death of a baby through early pregnancy loss, stillbirth, or in the first few months of life.

Web address: http://www.nationalshareoffice.com

Mailing address: National Share Office

St. Joseph Health Center

300 First Capitol Drive

St. Charles, MO 63301

Toll-free phone: (800) 821-6819

Suicide Awareness Voices of Education (SAVE) — information on suicide prevention, depression, and the links between suicide and depression; what to tell children, coping with loss, responding to survivors and other educational materials

Web address: http://www.save.org/

Mailing address: 8120 Penn Ave. S., Suite 470

Bloomington, MN 55431

Phone: (952) 946-7998

National Suicide Prevention Lifeline: (800) 273-8255

For More Information about End of Life Resources Feel Free to Contact the Presbyterian Health Network (PHN)

a network of the Presbyterian Health, Education & Welfare Association (PHEWA)

www.pcusa.org/phn

Contacts for More Information

"Sowing Seeds of Wellness in the Presbyterian Church, U.S.A."

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