


Spiritual Care Services

Communicating
with a Loved One
at the End of Life

UCSF Medical Center



UCSF Children's Hospital

A decorative graphic in the top-left corner of the page shows a branch with several yellow leaves, rendered in a soft, semi-transparent style against the light yellow background.

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sometimes this period in a family's life may be used
for tremendous growth, healing and transformation.

How to Communicate With Your Loved One

*I*t can be very challenging to bring up your concerns about your loved one's dying. People fear that it will be interpreted incorrectly, or that it will create more suffering and fear for the dying person. Although fearing such conversations is normal, in most cases an honest and open dialog about your concerns is experienced as relieving and helpful by the patient.

The following guidelines may help in creating the conversation:

- ☛ Take advantage of any openings that may arise. Often times the patient him/herself will be afraid to raise concerns as a way to protect you from difficult feelings. Be alert and open to any indication that your loved one wishes to talk about things such as the future, the meaning of one's life and death, forgiveness, goodbyes, getting things in order, etc.
- ☛ Include the past, present and future in your conversations. Many people want and need to talk about the past as a way to make sense of their lives and to understand

its meaning and purpose. Concerns about how things are going in the present, including any hopes and fears that the person may have, is grounding and communicates commitment to continuing communication. And although it may feel awkward, allow the conversation to include references to the future time when your loved one will no longer be alive. Many people need to talk about life after they are no longer with us and are thwarted by our attempts to shield them from the pain of their grief about leaving.

- ☛ Planning and discussing the dying person's treatment choices and goals of care can alleviate much anxiety at the end of life and free energy for the important spiritual work of dying. A person who feels heard and understood about what they want in terms of comfort care continues to feel dignity, and the family gets to share the gift of shaping this last life passage according to the dying person's wishes.
- ☛ Allow room for all levels of the discussion, from practical considerations to emotional spiritual dimensions.



Spiritual Dimensions of the Dying Process

We all sense that dying is much more than a medical event; sometimes this period in a family's life may be used for tremendous growth, healing and transformation. Although this aspect of dying is unique for each person, there are patterns that can be recognized in terms of the spiritual needs of both the patient and the family. These spiritual needs are described as a sense of belonging, meaning and reconciliation.

Belonging is a universal need that is often more acute at the end of life; it is the need for community, connection and to feel contained within the sheltering care and comfort of people who share love. The need to feel connected and cared for is one of the most important needs of the dying. Belonging can be communicated with words; sharing memories, stories and laughter; and through comforting physical contact.

The need to discern and share the deepest meanings contained within one's life journey is one of the core

needs of the dying. Sometimes this is expressed as a search for the values that have guided one's life; other times, one's relationship to a Higher Power, faith tradition, or spiritual practice comes into focus or under question. Whatever form this searching takes, it is most important that the process of making meaning be allowed to unfold in whatever way is most natural to the dying person. Family members can help by supporting this search, and by recognizing its healing power.

Forgiveness is the need for finishing any unfinished relationship issues so the dying person can find a sense of peace in his/her heart. Often this need will be expressed as a desire to make amends. Even if you do not think there is anything to be sorry for, family members can help by simply accepting amends if they are made by the patient. Likewise, there may be expressions of regret or remorse that are very healing to have aired. Another aspect of this spiritual need expresses itself in the making of legacies and gifts. Letting your loved one know that

his/her wishes will be carried out can be very healing and comforting to the dying person.

Belonging, meaning and forgiveness are the core spiritual needs, and they come into focus most clearly in relationships of intimacy and love. Researchers in palliative care have discovered five areas of concern for people who are dying that can bring deep peace and comfort in the area of relationship healing. These areas are contained in the following statements.



Thank you

I love you

I forgive you any hurts you have caused me

Please forgive me any hurts I have caused you

Goodbye



These 5 statements can be used as guideposts in the verbal and non-verbal exchanges we have with our dying loved ones. Speaking truthfully, allowing tears if they are there, and staying close are the greatest gifts we have to give to our loved ones in their dying.

Simple acts of kindness are also experienced by the dying as expressions of the presence of love in your relationship. Gentle touch, simple attention to the physical needs of the dying, and soft words of encouragement, affirm your care and connection. As the process continues, simple presence, calmness and silence allow for the deepest spiritual dimensions of the death experience to unfold.



What is Grief?

Grief is one of the deepest pains that we can ever experience. It is the normal and adaptive process of accommodating to any experience of loss or unwanted change. It is always a shock, whether the loss was expected or not. Although each person's expression of grief is unique, it is a universal human experience; none of us who have loved another can escape the pain of loss or the process of grieving that goes with it.

The stress of grief is huge; every aspect of one's being—physical, emotional, cognitive and spiritual is affected. Everything in one's life is changed by loss, and helping us to cope with and later adjust to all of those changes is the healing purpose of the grieving process.

So although we live in a time when the social norm is focused on “getting over it,” grief is a process that deserves our utmost respect. Neither we, nor others, can brush aside, judge or placate away our grief. Although there are wide variations in individuals' particular responses and methods of coping, there are also some universal patterns in the process. The following list

includes some of the possible expressions of grief.

- ✦ Intense feelings of sadness, anger, fear, despair, loneliness, guilt, resentment, relief, regret and irritability
- ✦ Numbness, disbelief, withdrawal, isolation, restlessness, difficulties concentrating, disorganization, fear of being “crazy” and lowered self-esteem
- ✦ Physical symptoms including insomnia, muscle tension, pain or heaviness in the heart area, loss of appetite and exhaustion
- ✦ Atypical responses to friends, offers of help, or usual sources of comfort
- ✦ Searching for the deceased, or finding oneself expecting him/her to return
- ✦ Moodiness, unexpected crying jags, feelings of anger over being left by the person who died

These are all natural and normal grief responses when a person suffers a loss.



Understanding Your Grief Journey

*I*t can be helpful to think of your grief as a journey through an unknown land with trails that are often difficult to find. The following are some markers to help you know that, although you are experiencing loss, that does not mean you are “lost.” There are some guideposts on the journey, placed there by others who have traveled this path. Here are some of them:

- ☛ There are no right or wrong emotions. Strong emotions are normal and it is common for us to judge ourselves for having some of them. Much depends on the unique relationship one had with the person who is gone, the circumstances surrounding the loss, and our own personal comfort with strong emotions. Accepting the whole range without self-criticism is one of the major challenges of grief.
- ☛ Deep emotional pain is an essential part of the process. Though it is understandable to try to avoid the intense distress connected with the grief process, feeling and processing all that arises is a necessary part of healing.

“Grief is a tidal wave that overtakes you; smashes down upon you with unimaginable force, sweeps you up in its darkness, where you tumble and crash, to be thrown out on an unknown beach, bruised, reshaped.”

We must feel it to heal it. Numbing out with substances, work, keeping busy or other avenues of escape will only prolong the pain and delay the process of healing.

- ☛ Mourning is hard work, often invisible to others. No one else can feel the pain in our hearts, nor heal it, though their support and encouragement can help.
- ☛ There is no right or wrong timing to grief. The death of a loved one naturally brings about emotional, physical

and spiritual pain. But encountering this pain all at once would be overwhelming, so most often we touch into and out of it, in doses. Sometimes we need to distract ourselves; other times, we need to dive into it. Each of us has a unique way and timing. Respect this natural rhythm of grieving. In general, however, grief is a process that takes longer than anyone expects.

- ☛ Guilt, real or imagined, is a normal part of grief. It surfaces in thoughts and feelings of “if only.” In order to heal this guilt, it is most helpful to share these feelings with trusted others. Ultimately, one must forgive oneself for whatever ways we have failed in our relationship with the deceased. This is a challenging process that takes time and effort.
- ☛ Telling one’s story is a natural way to process grief. Seeking and accepting supportive people to listen to our stories is a vital part of successfully navigating the grief journey.
- ☛ Grief is a life altering experience that will continue to reverberate throughout our lives; we don’t “get over”

our grief, but instead, become reconciled to it. This means that the full reality of the death becomes a part of us. The sense of loss “softens,” but does not completely disappear. Realizing that the dead person will never be forgotten allows us the possibility that our own lives can and will move forward.

- ☛ When reminders such as holidays, anniversaries or other special memories are triggered, many people experience the grief once again, but typically the duration and intensity are less severe as reconciliation and healing proceed.
- ☛ Ultimately, grief transform us, but there is often a period of intense disorganization and distress before a sense of purpose and meaning return. During that time the bereaved may feel that there is nothing to live for and he/she may think about a release from this intense pain. Be assured that the pain will lessen and healing through grief will happen.



Bereavement Support Groups

Grief and bereavement support groups provide opportunities for you to discuss your experiences and learn about grief with others who have experienced similar losses. Although most groups are usually facilitated by the trained professionals, the true source of support is others who are also experiencing loss and grief.

Sometimes well-meaning friends or family try to protect the griever by not mentioning the dead person's name, or by removing reminders of the loss. This strategy communicates that the pain of dealing with the loss would be overwhelming. Often, although friends and family mean well, they may either be experiencing loss as well or simply do not know how to "be there" in the most helpful way. Because of one's extreme sensitivity during a time of loss, others' responses may be disappointing or feel hurtful. In this situation, especially, it can be very helpful to have a safe place to express your thoughts and feelings where you know everyone will understand and accept you.

Children and Grief

Children suffer grief when someone they know and love dies, though they may express their feelings somewhat differently than adults. Although they may seem relatively unaffected, they are processing their feelings through age-appropriate play and conversations. The age of the child determines the degree of understanding he/she will have, and adults need to modify their explanations and support to meet the developmental maturity of the child. It is not uncommon for children to feel left out of the experience of the adults, so a special effort needs to be made to help them find age-appropriate ways to participate in the events surrounding the death. Writing a letter to the loved one, drawing a picture, participating in the funeral or memorial service, or sharing stories and tears with others who are also grieving, helps them feel included and promotes their healing.



When You Might Need Extra Help with your Grief

Sometimes the natural process of bereavement can get shut down or go off track. The grieving process can be very tumultuous, but if, after a few months, you are experiencing some of the following symptoms, they may be indicators of the need for some extra support in the process:

- ☛ Being irritable and angry much of the time
- ☛ A sense of numbness or inability to feel sad that doesn't let up
- ☛ Feeling very anxious about your own or other loved ones' dying
- ☛ Preoccupation with the details surrounding the death
- ☛ Self-harming behaviors



When Someone You Care About is Grieving

Being with someone who is grieving can be difficult for us. Often there are no words that seem to touch the enormity of the griever's pain. The most important thing we have to give someone who is grieving is our caring attention. Some guidelines from others who have been on the receiving end of care follow:

- ☑ Don't minimize the loss with comments such as "She's in a better place now," "It was God's will," "Time will heal," or "I know how you feel." These kinds of remarks, though meant to help, seldom do.
- ☑ Don't think you have to say something. Your presence and caring are far more valued than most anything you can think of to say.
- ☑ Invitations to the griever to share memories, stories, feelings are most valuable. Offering a non-judgmental, accepting presence, even if what is being shared is repetitive, or painful, is very helpful.

- ☑ If you want to help in a concrete way, suggest one way to do that. Simply saying "call me if you need anything" will most likely not result in a request.

Please believe me, if you care, you can't go wrong.

Just admit that you care. This is what we search for.



Practical Considerations Immediately After Death

In the earliest hours and days of loss, there are countless decisions and details that must be addressed. Yet most of us are unprepared for dealing with such things under so much duress. This section of the booklet offers some guidelines, information and resources to help you during this time.

Depending on the circumstances and place of death, and your own inclinations at this time, your options for being with the deceased will vary. It is important to let people know what you want: whether to be present or not; time with family and friends in the room; or time alone with the person, to bathe or dress him or her; a prayer or ritual with a spiritual caregiver or clergy person; or a chance to say goodbye in your own individual way.

You will be asked to sign various forms according to the hospital or hospice policies in use. You may be approached to discuss the possibility of organ or tissue donation, in accordance with California law. Should this be desired,

your loved one's body will be treated with dignity and care, and the donation will not interfere with an open casket, if that is your wish for the funeral. There are some circumstances in which you or your physician may want to discuss having an autopsy performed on your loved one's body. Ask all the questions you may have in order to make the best possible decision about this difficult choice.

Members of the family will be asked to specify a funeral home for the transfer of the body. After one is selected and called, the funeral home will arrange to come to the home or hospital to take the body. If it will be a while before the funeral home personnel can come, and the death has occurred in the hospital, the body is moved to the morgue and is picked up there. You may or may not want to be present for this, as it can be a very intense experience of yet another level of the reality of the loss and the physical separation that comes with death. Funeral, cremation and/or cemetery arrangements will need to be made if the deceased had not made them

earlier. It is helpful if a trusted friend can help with these plans, as such decisions can be very challenging at this time. Family members usually go to the funeral home to make these arrangements. You may also wish to bring the clothing your loved one will be buried in to the funeral home at this time.

A certified copy of the original Certificate of Death is the only recognized legal proof of death-in the state of California. The funeral home or County Office of Vital Statistics can help you complete the necessary application. Such certificates may be required for obtaining life insurance; veterans or pension benefits; banking; wills and trusts; and dealing with the property of the deceased. It is helpful to bring the following information with you when you visit the funeral home:

- ☑ Name of deceased
- ☑ Date and place of birth

- ☑ Social Security number
- ☑ Father's full name and place of birth
- ☑ Mother's full name and place of birth



Spiritual Care Services

*U*CSF is committed to providing spiritual and emotional support to patients and families going through loss through the services of our Spiritual Care Department. Chaplains are trained to support people of all faith backgrounds, as well as those who follow no traditional faith. We can also arrange for services from representatives of particular faith groups if that is desired. Chaplains are available every day and can be reached at (415) 433-2273.



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UCSF Medical Center and UCSF Children's Hospital meet the special needs of our patients with disabilities by striving to provide equal access to our facilities and services. For information about accommodation options, please call Patient Relations at (415) 353-1936.