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Bereavement services

Mission Hospice offers bereavement services to help those who are grieving or facing the death of a loved one. Services include anticipatory grief support, check-in calls with the newly bereaved, support groups, and individual grief counseling. These programs are led by grief counselors, social workers, spiritual counselors, interns, and volunteers with special training in bereavement, and are open to anyone in the community.

Grief support allows people to:

- Express feelings of grief
- Talk about one's loved one
- Sort through the stresses and anxieties that may come with new roles and responsibilities of caregiving and loss
- Reflect upon one's natural strengths and use them to get through a difficult time
- Learn about the grief process

What is bereavement?

Although the word **bereavement** refers to the state of loss which results from the death of a loved one, our bereavement support actually begins as soon as a patient is admitted to our service. Loss and grief occur a long time before a patient dies. Both loss and grief are present (in one form or another) from the moment a terminal diagnosis is given and both, in most cases, continue to accumulate over the course of an illness. As a hospice agency, we are committed to supporting both our patients *and* their families as they experience these losses.

Supporting patient families

When nurse case managers and social workers do initial intakes, and as they and other members of the team follow the patients and their families over time, they identify the caregivers and family members closest to the patient and assess their bereavement risk. The bereavement risk (low, moderate, or high) is determined based on how difficult a time they are having now, and how difficult a time they are anticipated to have after the patient dies. Risk factors for bereavement include numerous elements including multiple losses in the family, family members in frail health, complex family dynamics, short course in hospice or with terminal condition, substance abuse and/or mental health issues, or children present in the home.

Those who seem to be at greater risk than average are offered additional emotional support while the patient is still alive, including:

- Extra visits from a social worker
- Visits from a spiritual counselor, as appropriate
- Supportive anticipatory grief counseling with bereavement counselor, either in the home or in our office
- Increased volunteer support

After a patient dies, social workers refer specific family members /loved ones (usually no more than two per family, and *family* however defined) to bereavement counselors, who follow identified family members with a specific care plan, including:

- An initial letter two weeks after the death that explains our bereavement services and provides an insert with information about our services and what to expect in grief
- Supportive telephone calls at two months and five months after the death (or more frequently, if needed, based on risk level)
- Notes sent to acknowledge important dates for the family (the deceased person's birthday and the one-year mark of the death)
- An invitation to our annual remembrance ceremony

Of course, all bereavement services are optional. Some families prefer to grieve privately or have adequate support systems. Family members have the choice to decline calls, mailings, and counseling.

Individual grief counseling

Mission Hospice offers individual and family counseling sessions to support patients and family members. Family members of our hospice clients receive eight free sessions; additional sessions for our hospice bereaved, and counseling for members of the general public located in our service area, are $100/session or sliding scale.

Our state license permits us to provide counseling only for family members living in California; we can provide referrals and resources for people who live outside of California.

Bereavement support groups

Mission Hospice offers a range of grief support groups, all free of charge and open to everyone in the community (within Mission Hospice's geographical service area, the San Francisco Peninsula and South Bay).

Current programs are always listed on our website:

www.missionhospice.org/events

and in our monthly *Community Connections* guide:

www.missionhospice.org/connections

Programs include drop-in support groups as well as specialized 8-week support groups, including special topics such as “Writing through Loss” and “Coping with the Holidays.”

Bereavement volunteers

Volunteers are key to our bereavement support. Experienced and trained volunteers call the low-risk family members, as well as co-facilitate some of the grief support groups. Volunteers also assist in writing cards for birthdays and “anniversaries,” and help at events such as our annual remembrance ceremony. Volunteers may also assist with specific office tasks such as organizing a library, help with mailings, etc.

Volunteers may be exposed to anticipatory grief prior to the death of a patient. Some volunteers may have limited contact with the family following the death of a patient. It is important for volunteers to have some background in the grief process to help guide them in interacting with bereaved family members with sensitivity, compassion, and authenticity.

About loss and grief

Anticipatory grief

Anticipatory grief is grief that occurs prior to an actual loss. It is most often used to refer to the grief that someone is experiencing as they anticipate the death of a loved one. But, of course, patients themselves experience anticipatory grief as they face their own death and all the many losses associated with it. It is important to note that there are many losses for patients and families that occur during the course of an illness – from the moment they receive a diagnosis to quitting work, losing a sense of self (appearance, function, identity), becoming dependent, etc. – losses that they are grieving before death.

Anticipatory grief counseling with the patient is usually done by the social worker, but may also be done by spiritual counselors or bereavement counselors. This counseling allows the patient or family member to talk about impending death (their own anticipated death or that of their loved one), what “unfinished business” the patient and family members have, and how to prepare emotionally, spiritually, and practically for the death.

In working with dying patients and their families, the theory of *Maslow’s hierarchy of needs* can be a helpful framework to prioritize interventions.

Maslow’s Hierarchy of Needs – for hospice patients

1. **Physical needs**: biological needs, pain, and symptom control, meeting basic life needs, such as breathing, eating, toileting
2. **Safety issues**: security, both physical and emotional, to be free of fears about too much pain, dying, choking (e.g. lung cancer), drowning (e.g. pulmonary edema), anxiety, stable place to live, generally feeling safe

3. **Love and belonging**: love for patient is reaffirmed by family/caregivers despite illness, relationship issues, social network, family issues, giving and receiving affection
4. **Self-esteem**: dignity, not being a burden, respect for past and present value of the person, prestige of societal recognition, narratives of life work
5. **Self-actualization**: existential issues, what gives meaning and value to life, personal journey and growth in illness, maximizing unique potential in life – deep connection to others, nature, God, spiritual and religious issues, peace, transcendence, closure, perception of beauty, truth, goodness and sacred in the world – such experiences become highly motivating, helping people feel alive and enlightened

Key terms

Bereavement: The personal and social status of one who has had a loved one die. It is one's position as an individual in relation to the person who died, and to others around that individual.

Grief: A natural reaction to the loss of a loved one. It may be a combination of physical sensations, thoughts, feelings, extra sensory perceptions, social changes, spiritual questioning or affirmation, and behaviors. It also can be a time for personal growth and development. Each person's journey through grief is unique.

Grieving: The emotional processes needed for healing to occur before, during, and after a loss; nature's way of healing a broken heart.

Loss: An occurrence or event that shatters dreams that were core to one's existence (Ken Moses, Ph.D.).

Mourning: The process of adapting to a death. It is a process with cycles, such as denial, anger, fear, depression, etc. It is also referred to as *the ritual response* to death and is culturally conditioned.

What is grief?

Grief is expressed physically, emotionally, socially, and spiritually.

- **Physical** expressions of grief often include crying and sighing, headaches, loss of appetite, difficulty sleeping, weakness, fatigue, feelings of heaviness, aches, pains, and other stress-related ailments.
- **Emotional** expressions of grief include feelings of sadness and yearning. But feelings of worry, anxiety, frustration, relief, anger, or guilt are also normal.
- **Social** expressions of grief may include feeling detached from others, isolating oneself from social contact, and behaving in ways that are not typical for the mourner.
- **Spiritual** expressions of grief may include questioning the reason for the loss, the purpose of pain and suffering, the purpose of life, and the meaning of death.

Factors that impact the grieving process

1. **The nature of the relationship with the deceased**
    - The strength and security level of the attachment
    - The type of relationship: mother/father, child, sibling, grandparent/grandchild, friend, etc.
    - Any ambivalence or conflicts in the relationship
    - Dependencies (emotional, financial, etc.)

2. **The type of death and circumstances surrounding the death**
    - Natural, accidental, suicidal, or homicidal
    - Suddenness or expectedness of the death
    - Violent or traumatic death
    - Multiple simultaneous deaths (or within a short time period)
    - Was the death preventable, or believed to be so?
    - Ambiguous death: (not sure if s/he is dead or alive, i.e. MIA, kidnapped, etc.)
    - Stigmatized death, i.e. AIDS, suicide, drug overdose, etc.

3. **Personality variables of the bereaved**
    - Age and gender
    - Uniqueness of temperament and coping style
    - Life experience, birth order, only child, etc.
    - Ego strength: self-esteem level, general mental health
    - Physical health
    - Assumptive world view: beliefs and values (cultural, religious, spiritual); the ability to make meaning from a tragedy
    - Past grief experiences

4. **Social variables**
    - Support network availability (family, friends, religious/spiritual affiliation, community, etc.)
    - Cultural or ethnic influences and expectations
    - Disenfranchised grief caused by a socially stigmatized relationship

5. **Other stressors on the bereaved**
    - Multiple losses over a lifetime and/or relatively short time period
    - Secondary losses (of job, home, etc.)

Grief is universal and personal: Respect differences

Everyone grieves differently – there is no right or wrong way to grieve. Each one of us grieves in our own way, with our own intensity and at our own pace.

What may be a profound loss to one person may be a less significant loss to another. For instance, one person may be devastated when they lose their ability to drive a car while another person may relinquish driving without difficulty. That same person may have a very difficult time accepting the need to use a walker. What defines a significant loss varies from person to person.

Everyone copes with loss differently. For instance, one person may have a need to turn inward and pull away from people, while another may have a strong need to share their grief with others. Some may grieve with a great deal of intense emotion, while others may process their grief in a more cognitive way or engage in activity that addresses their grief. For others, grief comes out in the body (somatic), with symptoms such as tension headaches, digestive problems, or insomnia.

The most common symptoms of grief are sadness (tearfulness, preoccupation with deceased, yearning, pining, overwhelming flood of energy-consuming sorrow) and anxiety (fear of being abandoned, fear of one's own death and suffering, fear of living alone, fear of the future and of the unknown).

It is important to remember these differences, so we don't make unfair judgments about how one is grieving and coping with their losses.

Grief as opportunity

Loss and grief and end-of-life issues provide much opportunity for personal growth – people can find their strengths and use their loss in a transformative and meaningful way. Much of this growth may occur over time; premature mention of grief's potential may feel empty to an acutely grieving person. Gradually, with *adaptive integration* of the loss, and moving forward successfully in life – with other relationships, work/purpose, and life enhancement (finding joy) – a grieving person (*griever*) can gain confidence in their ability to cope with challenge. Personal growth often occurs when a grieving person has found a sense of meaning to their loss – either spiritually or emotionally – giving rise to lessened pain and greater peace. When it happens, it can be quite amazing to witness.

"He who has a why to live
Can bear almost any how."

– Friedrich Nietzsche

Myths and facts about grief

Myth: The pain will go away faster if you ignore it.

Fact: Trying to ignore your pain or keep it from surfacing will only make it worse in the long run. For real healing it is necessary to face your grief and actively deal with it.

Myth: It's important to be "be strong" in the face of loss.

Fact: Feeling sad, frightened, or lonely is a normal reaction to loss. Crying doesn't mean you are weak. Showing your true feelings can help them and you.

Myth: If you don't cry, it means you aren't sorry about the loss.

Fact: Crying is a normal response to sadness, but it's not the only one. Those who don't cry may feel the pain just as deeply as others. They may simply have other ways of showing it.

Myth: Grief should last about a year.

Fact: There is no right or wrong timeframe for grieving. How long it takes can differ from person to person.

Children and grief

Some of Mission Hospice's bereavement counselors specialize in supporting grieving children. It is also helpful for volunteers to understand some basic developmental grief responses of children.

Age and emotional development influence the way a person grieves a death. Most grieving children have three main concerns (the 3 C's):

> **Care**: Kids need to know who is going to care for them.
>
> **Contagion**: Kids need to know they won't catch the disease that made their loved one die.
>
> **Cause**: Kids need to know they didn't do anything to cause the death.

Children younger than age 7 usually perceive death as separation. They may feel abandoned and scared, and they may fear being alone or leaving people they love. Grieving young children may not want to sleep alone at night, or they may refuse to go to day care or school. Children under age 7 usually are not able to verbally express their feelings; instead, they tend to act out their feelings through behaviors such as refusing to obey adults, having temper tantrums, or role-playing their lives in pretend play.

Children between the ages of 2 and 5 may develop eating, sleeping, or toileting and bed-wetting problems.

Children younger than age 2 may refuse to talk and be generally irritable.

Children between the ages of 7 and 12 often perceive death as a threat to their personal safety. They tend to fear that they will die also and may try to protect themselves from death. While some grieving children want to stay close to someone they think can protect them, others withdraw. Some children try to be very brave or behave extremely well; others behave terribly. A

grieving child may have problems concentrating on schoolwork, following directions, and/or doing daily tasks. Children in this age group need to be reassured that they are not responsible for the death they are grieving.

Teens perceive death much like adults do, but they may express their feelings in dramatic or unexpected ways. For example, they may join a religious group that defines death in a way that calms their feelings. They may try to defy death by participating in dangerous activities such as reckless driving, smoking cigarettes, drinking alcohol, taking illegal drugs, or having unprotected sex. Like adults, preteens and teens can have suicidal thoughts when grieving. Warning signs of suicide in children and teens may include preoccupation with death or suicide or giving away belongings.

Guidelines for supporting grieving children:

- Answer their questions, even the hard ones. It's okay to say, "I don't know."
- Give the child choices, whenever possible.
- Talk about and remember the person who died.
- Give the child permission to share his or her feelings about the deceased.
- Respect differences in grieving styles.
- Give a child options to express him/herself: art, music, sports, play.
- Listen without judgment.
- Hold a memorial service and allow for saying goodbye.
- Allow breaks from grief – to play, focus on friends, school, and fun.

When does grief counseling end?

Although Mission Hospice offers eight free counseling sessions to bereaved family members, we all know grief does not go away after eight weeks, or eight sessions. A person begins to feel "healed" when they realize they have their own resources to cope with their loss. Those resources may be external (friends, family, sense of purpose) or internal (self-soothing, perspective, faith, confidence, self-efficacy, resilience). The acute symptoms of grief, such as insomnia, fatigue, physical sensations of panic or anxiety, and chaotic and uncontrollable emotions will have reduced, with more frequent periods of routine, stable emotional health. The intensity of the pain of grief will have lessened, and the person will focus less on the pain of loss and more on the love that they once had with their loved one. The bereaved recognize there may be occasional times of intense grief, such as during anniversaries, but they will feel confident enough to handle them on their own, perhaps with connection to their own personal support system.

Coping with feelings

When clients/family members show difficult emotions (fear, anger, sorrow, shame), we can:

- Normalize
- Generalize
- Personalize

Our job is to *allow and accept* the expression of emotions. Some feelings are not acceptable if they intimidate, threaten harm for self or others. Look at emotions with curiosity and friendliness.

Self-care for caregivers

Being a caregiver can be stressful, emotional, and exhausting. Finding ways to take care of oneself while caring for another can be challenging. Our social workers help caregivers develop coping abilities, manage family relationships, and recognize sources of stress – as well as find ways to relax. We also help caregivers learn to grieve, both before and after their loss.

Volunteers also need to care for themselves; you will find more tips for self-care at the end of this manual.

We encourage caregivers, including volunteers, to:

- Tend to their own health
- Get plenty of sleep and eat well
- Exercise regularly
- Find ways to relieve the stress that accompanies caregiving
- Seek and accept help
- Know their limits
- Accept and talk about their grief

It's important for caregivers to identify what they need or want help with. Some people find it difficult to ask for – and accept – help.

When caregivers get overwhelmed:

- Naming emotions is the first way to control them: "If we don't know what we feel, we can't feel what we don't know."
- Be mindful (not judging but accepting) of emotions.
- Emotions are teachers, not burdensome problems.
- Emotions are energy.
- When difficult emotions are stopped, denied, energy can become toxic.
- "Emotional energy unimpeded flows in the direction of healing." – Miriam Greenspan
- Emotions live in the body; be mindful of physical signs of stress.

- Our goal as human beings is to let ourselves experience strong emotions and also realize there may be times when we need to put on hold experiencing them in order to continue functioning. This is called compartmentalizing.
- We are in a continual struggle to balance stepping forward and taking action to deal with our difficult emotions and meet the demands of daily living, and also stepping back to rest and re-energize ourselves.
- As a volunteer, it is okay to show your empathy, including tears, as long as your emotions do not take away the focus from the client/family.
- Your reactions to suffering, illness, dying, grief, and death deserve to be heard and are also your strengths.

Practical ideas for managing difficult emotions in the moment:

- Deep breathing
- Mindfulness
- Hand over heart gesture / soothing gestures
- Re-framing/perspective
- Prayer
- Guided imagery – imagining positive experiences
- Social support
- Safe touch, hugging (human or animal!)
- Writing
- Music
- Art
- Exercise

Things to watch out for:

- Numbing. “It’s too much.”
- Shutting down. “I don’t care.”
- Burnout. “When is this over?”
- Irritability. “He bugs me.”
- Depression. “I’m too weary.”

Bereavement is a process, a journey, with many paths to walk, each unique to the griever. At Mission Hospice, our bereavement program is designed to meet, as best we can, the specific needs of our bereavement clients, through phone contact, letters and cards marking significant occasions, counseling sessions, and/or support groups.

We are honored to be a part of the healing that comes from active, compassionate engagement with our grievers, knowing that we, too, have been and will be in their shoes. It is humbling, and it is a privilege.

Mission Hospice Criteria for Bereavement Risk Levels, Pre- and Post-Death of Patient

This is a clinical tool for Mission Hospice Bereavement Counselors to assess the bereavement risk levels of a patient's loved ones. **As a volunteer, you will not be assessing bereavement risk,** but you may find this helpful.

At least three (3) criteria determine a risk level. Where there are criteria in more than one risk category, the clinician will err on the side of the higher risk level.

Low risk

- ☐ No substance / alcohol abuse
- ☐ No suicidal ideation and/or homicidal ideation
- ☐ Understands and/or accepts diagnosis / prognosis
- ☐ Affect and behavior appropriate to situation
- ☐ Denial not dysfunctional
- ☐ Healthy relationship with patient and/or other family members
- ☐ Minimal complications to physical and/or mental health
- ☐ Good support system in place regarding family, friends, social groups, faith community
- ☐ Spiritual pain absent or negligible

Moderate risk

- ☐ Evidence of some substance / alcohol abuse, client still functional
- ☐ No suicidal ideation and/or homicidal ideation
- ☐ Trouble understanding and/or accepting diagnosis / prognosis
- ☐ Affect and/or behavior causing moderate level of dysfunction
- ☐ Denial affecting some ability to cope with patient's condition
- ☐ Some level of dysfunctional relationship with patient and/or other family members
- ☐ Some complications regarding physical and/or mental health
- ☐ Inadequate support system

- ☐ Multiple losses
- ☐ Spiritual pain present with mild to moderate degree of client dysfunction
- ☐ Short-term diagnosis and/or patient's short stay on service
- ☐ Children in the home
- ☐ Alienated from cultural supports
- ☐ Difficult end-of-life experience

High risk

- ☐ Multiple high risk factors including substance/alcohol abuse, causing dysfunction for client
- ☐ Active suicidal ideation (SI) and/or homicidal ideation (HI)
- ☐ Unable to understand and/or accept diagnosis / prognosis
- ☐ Affect and/or behavior causing significant level of dysfunction
- ☐ Denial significantly impacting client's ability to cope with patient's condition
- ☐ Significant dysfunctional relationship with patient and/or other family members
- ☐ Significant complications to physical and/or mental health
- ☐ Multiple losses, some may be traumatic
- ☐ Poor or non-existent support system
- ☐ Spiritual pain significantly impacting client's ability to function
- ☐ Children in home/parent death
- ☐ Significantly alienated from cultural supports
- ☐ Traumatic end-of-life experience

As always, clinical judgment should guide use of above risk level categories and criteria.