# Bereavement Packet

Support for today and the days to come.



Adventist Health Portland

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As you find yourself walking a path you never wanted, you may have a lot of questions and concerns. Please know you're not alone. Our providers and staff are here to help however we can.

Death isn't something our culture talks much about. Most of us have little idea what to expect as our loved one begins to let go. We have no idea what steps to take as we enter an uncertain future.

This guide can be a resource for you in the days to come. It gives you some idea what to expect and offers ideas for how to take the next steps in your journey with loss and grief.

Always know we are here to support you. If you would like the support of a chaplain, please reach out to spiritual care services at 503-251-6105 anytime.

# What to expect when your loved one is dying



Although each death is unique to the person, there is a common final pathway that most people travel. This pathway includes:

- Social changes, like redefining self within the context of relationships.
- Emotional changes, including addressing the inevitability of death and attempting "closure."
- Spiritual changes, such as reviewing life, reflecting on meaning, addressing forgiveness and reconciliation, and making one's peace.
- Physical changes as the body prepares to shut down and "let go" to die.

It is not unusual for patients and families to experience a variety of emotions during this time. Our spiritual care team is always available to you and your loved one when you want us. We encourage you to:

- Focus on the present the "here and now" so you don't miss what is real in the moment.
- Share with your loved one the invaluable gift of your quiet presence.
- Be gentle with yourself during this time of letting go.
- Allow your health care team to support you as you desire.

#### Specific changes to expect

As death nears, many people go through changes. Your health care team is here for you to answer any questions you have. Here are some things you should expect.

**Social withdrawal.** Pulling away is normal as the person becomes less concerned about their surroundings. Separation begins first from the world – no more interest in newspaper or television. Then they begin to separate from people – neighbors and friends first, then children, grandchildren and others most loved. With this withdrawal comes less of a need to communicate with others, even with close family.

**Decreased interest in food.** The person will have a decreased need for food and drink as the body prepares to die. This is one of the hardest things for some families to accept. A gradual decrease in eating and appetite, even for favorite foods, is typical. Interest may come and go. The person is not starving to death; this reflects the underlying disease. Liquids are often preferred to solids. Follow your loved one's lead and do not force feed.

**Increased sleep.** The person will spend more and more time sleeping. It may be difficult for them to keep their eyes open. This is due to a change in the body's metabolism because of the disease. We encourage you to spend more time with your loved one during those times when they are most alert — even if that's in the middle of the night.

**Disorientation.** The person may become confused about time, place and the identity of people around them. While the person may not be distressed, this disorientation is frequently distressing to the family. Gently orient the person if they ask. There is no need to "correct" the person if they are not distressed.

**Restlessness.** The person may become restless and pull at the bed linens. These symptoms reflect a change in the body's metabolism. Talk calmly and assuredly with your loved one so you don't startle or frighten them. If they are highly restless or agitated, medications can be given to help them relax and rest more comfortably.

**Decreased senses.** Clarity of hearing and vision may decrease. Soft lights in the room may prevent visual misinterpretations. Never assume that your loved one cannot hear you. Hearing is the last of the five senses to be lost.

**Incontinence.** Losing control of urine and bowel movements is common. The nurse can help place absorbent pads under your loved one for more comfort and cleanliness, or a urinary catheter may be used. The amount of urine will decrease, and the urine becomes darker as death nears. "My flesh and my heart fail, but God is the strength of my heart and my portion forever." Psalm 73:26



### Near death awareness (NDA)

This describes a dying person's experiences as death approaches. There are two broad categories:

- Attempts to describe what dying is like: Some people describe seeing family members who have already died. Some people describe beckoning or welcoming. The language people use to communicate NDA may be symbolic. Some talk about preparing for travel or change.
- Requests for something to ensure a peaceful death: This might include closure in a personal or spiritual relationship, removal of a barrier to achieving closure, and/or preparation for death via specific items or rituals. We encourage you to gently ask your loved one about messages you don't understand. Accept and validate what your loved one is telling you – don't challenge or argue. If you don't know what to say, say nothing. Just be present.

Near death awareness (NDA). See sidebar.

A final surge of energy. Often when people are dying, they will reach a period when it seems they're getting better. Your loved one may wake up and may be able to communicate with you. These surges can last for a few hours to a few days. Though it can be confusing to see your loved one with renewed vitality, keep in mind that this is a normal part of the dying process. Your loved one may not actually be getting better. The final surge of energy is often a good time to gather your family and close friends to say final goodbyes.

#### Physical changes as death approaches

#### Specific physical signs may cue you that death is near.

- Blood pressure decreases, and the pulse may increase or decrease.
- Body temperature can fluctuate; fever is common.
- Perspiration may increase and may include clamminess.
- Skin color changes: flushed with fever, bluish with cold, possible pale-yellow pallor (not jaundice).
- Breathing may increase, decrease or become irregular. There may be periods of no breathing (apnea). Respirations often become shallow, with less rise and fall of the chest, and your loved one may do more breathing through their mouth.
- Congestion may cause a rattling sound in the lungs and/or upper throat because the patient is too weak to cough or clear their throat or cough. Congestion can be affected by positioning, may be very loud, and sometimes just comes and goes. Elevating the head of the bed and swabbing the mouth with oral swabs gives comfort. If congestion is severe, medications can "dry up" excess secretions.
- As blood circulation decreases, arms and legs may become cool to the touch. Hands and feet become purplish, while ankles and elbows become blotchy.
- People often enter a coma before death and don't respond to voice or touch.

#### Signs death has occurred

- No breathing or heartbeat.
- Loss of control of bowel and bladder.
- No response to voice commands or gentle shaking.
- Eyelids slightly open; eyes fixed on a certain spot.
- Jaw relaxed and mouth slightly open.

# What do we do now?

#### Important information



This can be a difficult and confusing time. Don't hesitate to ask for the information and help you need. We are surrounding you with experienced people who are eager to help and guide you through this difficult time and give you the answers you need.

#### What to do first

- **Request a chaplain:** You may want to request a chaplain to assist with grief issues by calling the hospital switchboard (dial 0) or asking your nurse to contact the spiritual care department.
- Choose a funeral home or mortuary: This packet also includes a list of possibilities, or you can use Google to look for options. When you have chosen a funeral home or mortuary, call the hospital switchboard (dial 0 from an internal phone or 503-257-2500 if you've left the hospital) to be directed to the appropriate person to whom to give that information. You can write the information here for easy reference.
- **Request autopsy or organ donation:** If you are interested in autopsy or organ donation, your nurse will be happy to provide the information you need.
- Write down the physician's information: Keep this information here so you can easily contact your loved one's doctor if you have questions later.
- **Collect all personal belongings:** Both you and your loved one may have personal belongings you will want to take with you when you leave the hospital.
- **Review this booklet:** Familiarize yourself with the other resources within this packet. This booklet can help to guide you and your family as you move through the coming days.

### Visiting the funeral home

If possible, take a friend, family member and/or your clergy person with you to the funeral home. It is helpful to have someone with a clearer mind to help with decision-making around funeral arrangements. Be prepared to give the funeral home information about your loved one, including:

- Full name, including any nicknames.
- $\bigcirc$  Date of birth and death.
- $\bigcirc$  Social Security number.
- Occupation and previous places of employment.
- Names of parents, children and other relatives and their relationship to your loved one – you may also need to provide your loved one's mother's maiden name.
- Military ID or discharge papers, if your loved one was a veteran.
- Religious, civic and/or other groups of which your loved one was a member.
- Name(s) of clergy you want to conduct the service.
- Location where you want to hold the service.
- Names of possible pallbearers and/or anyone you may wish to have speak about your loved one during the service.

If you're planning a burial rather than cremation, you'll need to bring a complete set of clothing, including underwear, but not shoes.

#### Going home

If you don't have anyone with you, try to contact a family member or friend to drive you home. Ask them to stay with you at your home or let you come home with them so you're not alone as you begin to process your loss. When you get home and as you are able, here are some next steps you may want to take:

- Call other relatives and close friends or ask close family member or friend to call for you.
- Reach out to your faith community and ask for your clergy or other members to support you and help you plan the funeral or memorial service.
- Ask someone else to keep a record of all incoming phone calls, food, flowers, notes and gifts so you can appreciate them later.
- Work with those closest to you to decide if you want to name a particular organization or charity where people can donate in your loved one's name.
- When appropriate, let employers, children's teachers and other connected groups know of your loss. Your loved one's work may have an insurance policy as part of its benefits package, so take the time to ask how to access that benefit.
- Let family members know that many airlines offer discounted fares when a sudden death has occurred. The airline may request the name of the person who passed and the name and phone number of the funeral home.

#### Planning a service

Here are some things to consider as you and your loved ones plan the service.

- Who will conduct the service?
- Where will you want the service to be held?
- Who should speak words of tribute?
- Will you want the service formal or informal? Any specific format or order?
- What special symbols or objects do you want to include?
- What readings, scriptural or other, would you like read? By whom?
- How will flowers (if any) be handled following the service?

- What music (if any) would you prefer?
  - » Organ selections/organist?
  - » Instrumental selections/instrumentalist?
  - » Vocal selections/vocalist?
  - » Hymns or songs to be played or sung?
- Will there be a reception afterwards?
  - » Where?
  - » How will people be informed?
  - » What would you like served?
  - » Who might manage this for you?
- Will there be honorariums or fees to be paid? To whom? Given by whom? What amounts?

If the date and time of the service are included in the newspaper obituary, you may want a friend or neighbor to stay at your house during that time to discourage anyone from taking advantage of your absence.

#### After service arrangements are completed

- Secure at least 10 certified copies of the death certificate from the funeral home for:
  - » Insurance companies
  - » Department of Motor Vehicles
  - » Bank accounts
  - » Mortgage company
  - » Creditors
  - » Airline or bus bereavement fares for out-of-town relatives, etc.
- Contact life insurance companies.
- Call Social Security to obtain death and survivor benefits if you or your child(ren) may be eligible.
- Call your attorney regarding the will and insurance policies and ask about next steps.
- Contact your bank regarding existing accounts.
- Contact (by phone or letter) creditors and credit card companies.
- If appropriate, secure information from county offices regarding probating your loved one's will.



"What we once enjoyed and deeply loved we can never lose, for all that we love deeply becomes part of us." Helen Keller

"Blessed are those who mourn, for they shall be comforted."

Matthew 5:4

# Signs and symptoms of grief

Grief is a natural part of life that starts at birth. The newborn baby leaves the warm, nurturing environment of their mother's womb. A child loses the security of home on their first day of school. A pet dies. Grandma dies; a schoolmate dies. A friend moves away. After graduation, a significant other says goodbye.

As we grow older, we may lose a parent, a child, a sibling, a spouse, a job, a house. There may be financial loss or the loss of one's reputation.

Loss of anything of value causes emotional pain, often with physical symptoms. Grief is a response to that pain. The process of assembling the pieces of a broken heart is hard work that is often misunderstood.

Grief shows up in many ways. Some of these are more recognized than others, but they all can be part of working through loss toward healing.

### Emotional/psychological effects

- Denial
- Guilt
- Anger
- Resentment
- Bitterness
- Irritability
- Disbelief
- Loneliness
- Hallucinations

- Sighing
- Nightmares
- Sadness
- Sense of failure
- Concentration on problems
- Failure to accept reality
- Time confusion

- Memory lapse
- Emptiness
- Fear
- Poor concentration
- Crying spells
- Preoccupation with the deceased

## Physical effects

- Exhaustion
- Loss of appetite
- Sleeping problems
- Lack of strength
- Weight loss
- Headaches
- Breathlessness
- Palpitations
- Weight gain
- Aching arms
- Restlessness
- Blurred vision

- Spiritual effects
  - Withdrawal from or increased – religious activity
  - Consolation provided by belief or scriptures
  - Searching for evidence of an afterlife
  - Change in priorities or values

- Seeking meaning in the loss itself
- Wavering of faith
- Examining the meaning of life
- Anger directed at clergy, religion or God
- No longer knowing what one believes
- Feeling like one is not supposed to have fear or feelings of grief is trusting in God
- Questioning:
  - » Why me?
  - » Where was God when I needed God?
  - » Where is God now?

- » Is this death God's will?
- » What do I do with my guilt?
- » Was my loved one saved?

- Other grief reactions
  - Suicidal thoughts
  - Feeling guilty when healing occurs and grief lessens
  - Using medication for sleep or calming nerves
  - Feeling protective of others, refraining from talking about the loss
- Assuming traits and mannerisms of loved one
- Crying easily and unexpectedly, even sobbing convulsively
- Shortness of breath, heaviness in the chest, frequent sighing
- Feeling the loss never happened, having a sense of unreality
- Feeling guilt over things done or not done, said or not said, in the relationship
- Preoccupation with the life of the deceased
- Wanting to talk a lot about the loved one, including the events surrounding the death
- Mood changing uncontrollably
- Feeling as if "losing one's mind"

- Social effects
  - Withdrawal from normal activity
- Isolation from spouse, family and/or friends

"Give sorrow words; the grief that does not speak knits up the o-er wrought heart and bids it break."

William Shakespeare



#### Steps for walking through grief

- Resume old and new relationships together and apart.
- Eat a well-balanced diet and drink plenty of fluids.
- Get a physical exam about four months after experience a loss to check for life-threatening diseases the body is at risk for during grief.
- Move daily by biking, walking, jogging, dancing, swimming - just keep moving.
- Maintain rest patterns, even if unable to sleep - read or journal while you're in bed. Try to resume normal sleeping patterns and avoid increasing work or other activities.
- Avoid long trips while your coping mechanisms are decreased.

- Keep a diary or journal of your thoughts, memories or mementos. You can also write letters, notes and poems to or about your loved one.
- Read books, articles and poems that help you understand and find comfort - avoid unsympathetic literature and technical medical publications.
- Avoid making big decisions or changes for the next year or two. Don't move or change jobs or relationships. Don't let others force decisions on you.
- Wait until you feel ready to do anything with your loved one's clothes or other belongings.
- Allow family and friends to share your grief and let them offer their support.

- Admit to yourself and your family when you need help. Accept others' help and give specific things they can do for you like bring you food or help with child care.
- Talk to your spouse, family and friends about your loved one and share your feelings. Tell them it is alright to mention your loved one or tell them if you prefer they didn't.
- Ask your clergy and faith community for help and support in renewing your faith and hope.
- Attend a support group so others who truly understand can offer support, help and hope.
- Remember four things that work with each other during this time: hope, time, love and healing.

Notes			

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Adventist Health Portland

OHSU Health accepts most health plans. OHSU Health is an equal opportunity, affirmative action institution.