

Caring For Your Loved One At The End Of Life:

Information for the Caregiver

Curriculum Module

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Educational Session

- A. Pretest
- B. Objectives for session
 - 1. Caregivers will learn what to expect in the dying process.
 - 2. Caregivers will learn what types of resources are available for caregiving.
 - 3. Caregivers will learn different coping skills for before and after the death of a loved one.
 - 4. Caregivers will better understand funeral planning and paperwork.
 - 5. Caregivers will receive a packet of information on other resources related to death, dying and bereavement.
- C. Information Knowledge Presentation
 - 1. Dying Process
 - a. What Do You Say...
 - b. The Dying Experience
 - c. Task work
 - 2. Resources
 - a. Activity: Support
 - b. Caregiver Resources
 - c. Hospice Care
 - d. Websites
 - e. Books
 - 3. Coping Skills
 - a. Activity: Do & Don't
 - b. Danger Signs
 - c. Coping Strategies
 - d. Preparation for Reaction to Loss
 - 4. Planning and Paperwork
 - a. Five Wishes
 - b. Funeral Planning
 - c. Final Details
 - d. Documents to Collect
- D. Poem
- E. Exercises and Techniques for Presentation
 - 1. Exercises:
 - a. Support
 - b. Do & Don't
 - 2. Techniques for Presentation: handouts and discussion of problems encountered and/or questions from group members.
- F. Action Plan Development: Caregivers will fill out the Action Plan Worksheet to prioritize what they need to do now, and what it will take to accomplish those things.
- G. Summary: Group leader will summarize issues discussed in session and answer any last questions from group members.
- H. Evaluation: Caregivers will participate in an evaluation of the session.
- I. Post-test.
- J. Information Packet
 - 1. Bereavement
 - 2. Remembering Exercise
 - 3. Symptoms of stress
 - 4. Caring for a Parent in your Home

Pre-Test

- 1) What is a common symptom one to two days to hours prior to death?
 - A. the patient may become agitated
 - B. the patients breathing stops
 - C. the patient may become very thirsty
 - D. The patient may have a surge of energy
- 2) What is the best response to take when the patients arms and legs are cool to the touch?
 - A. always use an electric blanket.
 - B. use warm blankets to keep them from feeling too cold.
 - C. nothing, it's alright for them to be cool.
 - D. adding layers of clothing.
- 3) T/F You know of resources in the community that provide respite care?
- 4) T/F Talking about and writing about your emotions is a common and acceptable coping strategy?
- 5) T/F Only people with large amounts of money and assets need to write a will?
- 6) T/F Within the first few weeks following the death numbness is a common physical reaction.
- 7) On a scale of 1-5, with 1 being not at all comfortable and 5 being as comfortable as you could imagine being – How would you rate yourself with respect to your level of comfort in talking with your loved one about dying?

1 2 3 4 5

If you wanted to be more comfortable with this, what would be helpful?

- 8) On a scale of 1-5, with 1 being not at all comfortable and 5 being as comfortable as you could imagine being – How would you rate yourself with respect to your level of comfort in caring for your loved one who is dying?

1 2 3 4 5

If you wanted to be more comfortable with this, what would be helpful?

The Dying Process

When caring for a loved one that is facing an illness it is important to be knowledgeable about the dying process. You will learn common symptoms of the dying experience starting with one to three months prior to death, one to two weeks, and finally one to two days to hours prior to death. It is not only important to know these symptoms and be familiar with them but also to understand the best way for you to react to each symptom. This will help you become comfortable with the dying process and will also help keep your loved one relaxed while experiencing the symptoms. Communication during the dying process may also become an issue for you and your loved one. Sections discussing what to say to a loved one who is dying and end of life tasks are included to help work through some of these difficult times.

The Dying Experience

What to Expect One to Three Months Prior to Death

1. Withdrawal and separation occurs

- First separation from world – no more interest in newspapers or television
- Then separation from people
- Withdrawing from everything outside of one's self is a time when the person sorts out and evaluates one's self and one's life.
- The evaluation of one's life is often done while eyes are closed, therefore sleep increases.
- Spending more time sleeping than awake becomes the norm.
- The need to communicate with others decreases
- Touch and wordlessness become more meaningful

2. Food

- When a body is preparing to die, it is perfectly natural that eating should stop.
- Gradual changes in eating habits occur; nothing tastes good, cravings come and go, and liquids are preferred over solids.
- Meats are the first foods that one begins to stop eating followed by vegetables and other hard to digest foods.
- Eventually soft foods are no longer eaten
- It is okay not to eat.
- Spiritual energy is needed not physical energy.

What to Expect One to Two Weeks Prior to Death

1. Disorientation

- Sleeping consumes most of the time at this point
- Keeping one's eyes open is difficult
- A person often becomes confused, talking to people, and about places and events, that are unknown to others.
- Conversations with people that have already died could occur.
- Picking at the bedclothes and agitated arm movements.
- One's focus is changing to prepare for death.

2. Physical changes

- Common for blood pressure to lower.
- Pulse beat changes from either the norm of eighty to upwards of one hundred fifty, or decreases anywhere down to zero.
- Body temperature fluctuates between fever and cold.
- Perspiration increases
- Skin color changes to a pale yellowish pallor.

- When one has a fever the skin could be flushed and when cold the skin may be bluish.
- Breathing changes; respiration may increase or decrease.
- Congestion can occur in the lungs and throat.
- Coughing may occur without having anything come up.

One to Two Days to Hours Prior to Death

- Sometimes there is a surge of energy
- A person may have been disoriented before and now talk clearly and alertly.
- A favorite meal may be asked for and eaten even though food intake has not occurred in days.
- A person may want to sit and visit with relatives even though they had not wanted to be with anyone for quite awhile.
- Spiritual energy for transition from this world to the next has arrived and is used for a time of physical expression before moving on.
- The surge of energy is not always obvious
- The one to two week signs of death that were present become more intense.
- Restlessness can increase due to lack of oxygen in the blood.
- Breathing patterns become slower and irregular.
- Breathing often stops for anywhere from ten to forty-five seconds before resuming again.
- Congestion can be very loud.
- Eyes may be open or slightly open but not seeing.
- Glassy and teary eyes
- Often a person is not responsive to their environment prior to death.

When Death Occurs

- what appears to be the last breath is often followed by one or two long spaced breaths and then the physical body is empty.

SIGNS AND SYMPTOMS OF APPROACHING DEATH

SIGNS AND SYMPTOMS

1. The arms and legs of the body may become cool to the touch and you may notice these areas and one side of the body becoming much darker in color. These symptoms are a result of circulation of the blood slowing down.

2. The patient will gradually spend more and more time sleeping during the day and at times will be difficult to arouse this symptom is a result of a change in the body's metabolism.

3. Your family member may become increasingly confused about time, place and identity of close and familiar people. Again, this is a result of change in the body's metabolism.

4. Incontinence (loss of control) of urine and bowel movements is often not a problem until death becomes imminent.

5. Secretions may become more profuse and collect in the back of the throat. You may have heard friends refer to a "death rattle." this symptom is a result of a decrease in the body's intake of fluids and inability to cough up normal saliva production.

6. Clarity of hearing and vision decrease slightly.

SUGGESTED RESPONSES

1. Keep warm blankets, not electric on the family member to prevent him/her from feeling overly cold.

2. Plan your times with your family member for the occasions when he/she seems most alert.

3. Remind you family member frequently what day it is, what time it is, and who is in the room talking to them.

4. Disposable pads or briefs may be placed under the incontinent patient.

5. Elevating the head of the bed with pillows or obtaining a hospital bed will make breathing easier. Ice chips, a straw and cool moist washcloths will relieve feelings of dehydration. Sometimes a dropper is helpful in giving very small amounts of fluids.

6. Keep lights on in room when vision decreases and never assume that the patient cannot hear you.

(SIGNS AND SYMPTOMS CONTINUED)

7. You may notice your loved one becoming restless and pulling at bed linen. Sometimes patients report having visions of people or things that no longer exist. these symptoms are a result of a decrease in the oxygen circulation of the brain and a change in the body's metabolism.

8. Your family member will have a decreased need for food and drink because the body will naturally begin to conserve energy which is expended on these tasks.

9. During the patients sleep, you will notice breathing patterns change to an irregular pace where there may be 10-45 second periods of no breathing. this is referred to as "apnea." This symptom is very common and indicative of a decrease in circulation and build up in body waste products.

10. You will notice that the amount of urine will decrease as death comes closer, and the urine may be much more concentrated.

7. Talk calmly and assuredly with the confused person so as not to startle or frighten them further. Encourage loved ones to talk about what they are seeing or hearing.

8. Offer small amounts of food and fluids. Do not give food or fluids if there is any question about the patients ability to swallow.

9. Elevating the head of the bed often helps the person breathe easier.

10. Keeping a record of when the patient urinates is helpful.

HOW WOULD YOU KNOW DEATH HAS OCCURRED?

Signs of death include

- No breathing
- No heartbeat
- Loss of control of bowel and bladder
- No response to shaking or shouting
- Eyelids slightly open
- Eyes fixed on a certain spot
- Jaw relaxed and mouth slightly open

Hospice of Holland Home

What Do You Say To Someone You Love Who is Dying.....?

This question is asked over and over and over by family members and friends. Unfortunately, there is no pat answer, no standard formula. Each person who is dying is not different. By simply being with the person and remaining sensitive to his needs you can help him along this unfamiliar path, and learn a bit about living too.

Some measures that you can take to ease the road to communication between you and your loved one are:

- Remember that each person has individual needs and feelings, often different from your own.
- Talk with your loved one; relate person to person. Be willing to be humorous and light-hearted as well as serious.
- Hear not only what your loved one is saying, but also what he is NOT saying. Use your ears, your mind, your eyes, and your heart to listen.
- Recognize that people have long-standing patterns of communication and different means of coping with stress. Allow them their individuality.
- Respond to expressed concerns with compassionate honesty. If you don't know the answer say so. Many times the person isn't really looking for an answer but simply wants to know what you think.
- Maintain a calm tone of voice and composure during interactions. Your control will improve the sense of control of others.
- Appreciate the person's need for privacy. Never force communication.
- Often it is helpful in stimulating conversation to encourage them to talk of past accomplishments – in other words, to “review” their life story.

It is natural for your loved one at this time to feel isolated and lonely. Closeness – touching and holding hands can help fill the need for affection and connectedness.

Developmental Landmarks and Task work
for the End of Life

Landmarks	Task work
Sense of completion	Transfer of fiscal, legal and formal social responsibilities
Sense of completion in relationships with community	Closure of multiple social relationships (employment, commerce, organizational, congregational) Components include: expressions of regret, expressions of forgiveness, acceptance of gratitude and appreciation Leave taking; the saying goodbye
Sense of meaning about ones' individual life	Life review The telling of "one's stories" Transmission of knowledge and wisdom
Experienced love and self	Self-acknowledgment Self-forgiveness
Experienced love of others	Acceptance of worthiness
Sense of completion in relationships with family and friends	Reconciliation, fullness of communication and closure in each of one's important relationships. Component tasks include: expressions of regret, expressions of forgiveness and acceptance, expressions of gratitude and appreciation, acceptance of gratitude and appreciation, expressions of affection Leave-taking, the saying goodbye
Acceptance of the finality of life – of one's existence as an individual	Acknowledgement of the totality of personal loss represented by one's dying and experience of personal pain of existential loss Expression of the depth of personal tragedy that dying represents Decathexis (emotional withdrawal) from worldly affairs cathexis (emotional connection) with an enduring construct Acceptance of dependency.
Sense of a new self (personhood) beyond personal loss	Developing self-awareness in the present
Sense of meaning about life in general	Achieving a sense of awe recognition of a transcendent realm Developing/achieving a sense of comfort with chaos
Surrender to the transcendent, to the unknown – "letting go"	In pursuit of this landmark, the doer and "task work" are one. Here, little remains of the ego except the volition surrender.

Stanton, Jana: Shuy, Roger: Byock, Ira. A few months to live: different paths to life's end. Washington, D.C. Georgetown University Press, c2001.

Anticipatory Grief-Tasks for the Families of Dying Patients

When someone close is diagnosed with a terminal illness, everyone begins to grieve. This anticipatory grief process can be confusing and difficult. On the one hand, you are attending to the needs of the ill family member and maintaining involvement with that person. On the other hand, you find that you begin to reinvest emotional energy toward how life will continue after the person dies. There is never enough time or energy to attend to these opposing needs.

The steps that you take to cope are called *tasks*. You will find yourself engaged in all of these tasks to varying degrees at the same time. Looking at each of these separately will help you to understand more exactly the demands of the situation and to make the best of family time, energy, and coping ability to deal with them.

TASKS

Fluctuating from Denial to Acceptance of the Illness and Death

Some denial of reality is healthy and necessary for you to function. It allows you to take in information at a more tolerable pace, and gives you a break for the emotional stress of the situation. Acceptance of what is happening will not necessarily bring peace.

Establishing a Relationship with Health Professionals

You may need to learn how to be constructively assertive, as well as find a way to deal with frustration. Family and caregiver conferences can help to reduce your anxiety by opening communication lines and giving you direct information. It may help to write your concerns down before meeting with caregivers.

Meeting the Needs of the Dying person

As the illness progresses, the patient's physical and emotional needs will change. Your task will be to help in the best way you can without taking away the patient's control or independence. Remember to ask him what he thinks he needs.

Maintaining a Functional Family Unit

When someone is sick, it means that everyone has to take on new roles and responsibilities. At the same time, it is important to maintain some of the common family routines. This gives you some security in the midst of chaos.

Living with the Emotions of Anticipatory Grief

During this time, both patient and family experience intense swings of emotion. Having information about these feelings and being aware of your own reactions help you begin to cope. It is important to let other family members know how you are feeling and what you need. There may be things that you prefer to discuss with someone outside the family.

Dealing with People Outside the Family

You have little energy at this time for outside relationships and everyone's reactions are unpredictable. Friends avoid the sick person. You resent others' stability and good fortune. People don't understand what you are going through.

Anticipating the Family's New Reality after Death

It is impossible to imagine the future. However, estate planning, dealing with different kinds of unfinished business, and building in emotional supports are things that can help you to prepare. The important thing is to do the best you can.

Finding Appropriate Hope

What you hope for throughout this time will change. Long-term plans need to be replaced by short-term plans; you find yourself giving up treatment aimed at cure for treatment that relieves symptoms. As you are able to accept the goal of comfort, you are taking a step toward acceptance of the inevitability of death.

Allowing the Dying Person To Be "At Risk"

Refusal to take medications or accept personal help may be very difficult for you to deal with, but it is important to recognize to patient's right to choose activities that may put him or her at risk. Those choices, however, should not put you at risk.

Making Decisions for the Dying Person

There may come a time when the patient is unable to make decisions for himself. Prior discussion, the use of a living will, or your knowledge of the person will help you represent his or her best interests.

Taking Care of Yourself

When you are focused on caring for someone else, it is hard to have energy for yourself and to see this as important. Building in time for self-care is crucial. Recognize that you have physical, emotional, and spiritual needs.

Remember

- These tasks are part of a process
- You will find that you are more aware of different tasks at different times
- There is no set procedure or need for completion
- The important thing is to do the best you can

"Medical Care of the Dying," 2nd Edition, Victoria Hospice Society, Victoria, British Columbia, Canada, 1993.

Resources

When faced with caring for a loved one who is dying, there most likely will be a need for help. The caregiver will most likely not be able to do it alone, and it may not be healthy to take all the caring needs upon themselves. First of all, it is important to realize that they are probably already doing many useful things on their own. They may have someone in their life who is very supportive and helpful. However, when that is not enough and the caregiver does not know where to go next, asking for help is okay. Following is a list of resources to help connect caregivers to agencies or publications that may be helpful.

Support I Have

People have many different areas of support. Sometimes when someone thinks of support, they think of organizational support groups or different groups. However, one of the main areas of support are the people closest to you.

List the names of people you could talk to about problems or struggles you were having, and check the appropriate box:

	Most of the Time	Some of the Time	Seldom
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Follow-up Questions:

What is it about this person that makes them easy to talk to?

Are there some things that you don't feel you could talk about?

What are they?

Caregiving Resources

Support Groups

- Area Agency on Aging of Western Michigan, 456-5664, www.aaawm.org, provides services to nine-county area
- American Association of Retired Persons, 800-424-3410, www.aarp.org
- Administration on Aging, 202-619-0724, www.aoa.dhhs.gov
- Alzheimer's Association, West Michigan Chapter, 800-893-8365, host support groups for caregivers of individuals with Alzheimer's disease and related disorders.
- Care Tree Adult Services, 464-3665, provides a support group for caregivers of Alzheimer's patients with special emphasis and education for the main caregiver
- Easter Seals of Michigan, 942-2081, provides programs for caregivers
- Gerontology Network, 456-6135, hosts the "Dementia Educational Support Series" as well as related educational programs
- Grand Rapids Community College Older Lerner Center, 234-3483, provides information on aging and caregiving
- Senior Health Dimensions, 957-9420, provides assessment, education and counseling to older adults and their relatives
- Support Group for Families and Friends of Aging Adults, 243-8116, 235-5029, provides education through speakers with expertise in aging and an opportunity for sharing
- West Michigan Caregivers' Alliance, 235-8501, provides a caregiver support-group series

Respite Care

- Elder's Helpers, 454-8305, 1417 Robinson Rd SE, Grand Rapids, MI
- AngelCare Inc., 245-8899, 2517 Burton SE, Grand Rapids, MI
- Home Instead Senior Care, 363-3967, 4950 Plainfield NE, Grand Rapids, MI
- Home Health Services Inc., 956-9440, 5363 44th St. SE, Grand Rapids, MI
- Sunshine Helpers, 456-6200, 435 Cherry SE, Grand Rapids, MI

Hospice

- Hospice provides a continuum of care provided by professionals and trained volunteers working together as a team to assess and meet the patients' and families' unique needs as the end of life draws near.
- It provides physical, medical, emotional, and spiritual care not only to the patient but also to his or her support system.
- Services provided include registered nurses, medical directors, attending physicians, social workers, chaplains, volunteers, and home health aides.
- Hospice care is covered through Medicare, including reimbursement for prescriptions, and granting a modest increase in reimbursement rates.
- Some private insurance plans cover hospice, and some states provide hospice benefits under Medicaid.

For more Information

- Hospice of Michigan at www.hom.com, 1260 Ekhart NE, 454-1426
- Hospice of Holland Home-Grand Rapids, 2100 Raybrook SE, 235-5113
- Heartland Home and Health Care & Hospice, 500 Cascade W. Pkwy, 942-7733
- Visiting Nurse Hospice, 1401 Cedar NE, 774-2702
- Hospice Foundation of America at www.hospicefoundation.org

Recommended Readings

- *Caregiving: The Spiritual Journey of Love, Loss and Renewal*, Beth Witrogen McLeod, 1999, John Wiley and Sons, Inc.
- *The Comfort of Home: An Illustrated Step-by-Step Guide for Caregivers*, Maria Meyer and Paula Derr, 1998, CareTrust Publications LLC.
- *Options for Supporting Informal and Family Caregiving: A Policy Paper*, Lynn Friss Feinberg, 1997, prepared for the American Society on Aging, available from Family Caregiver Alliance, (415) 434-3388.
- *Mainstay*, Maggie Strong, 1997, Bradford Books.
- *The Complete Eldercare Planner*, Joy Loverde, 1997, Warner Books.
- *How to Care for Aging Parents*, Virginia Morris, 1996, Workman Publishing Co.
- *Helping Yourself Help Others: A Book for Care-givers*, 1994, Rosalynn Carter and Susan Golant, Times Books, Random House.

Additional Web Sites

- www.caregiver.com – resources and links to other health-related Web sites
- www.caregivers.com – information and referral network for caregivers and seniors
- www.caregiving.com – moral support and links to related sites

Coping Strategies

There are many emotions you are probably experiencing, which have probably also been changing over time since you began caring for your loved one. When people feel overwhelmed by the demands put on them, sometimes they have difficulty seeing what a good job they are already doing and what other solutions are available. In this next section, we want to help you identify the useful ways in which you cope with your feelings and your situation. We want you to share these with each other, and then we will add some coping strategies that we have heard of.

Sometimes caregivers can burn out from putting so much time and love into helping their loved ones. In this next section, you will also learn what some danger signs are that can warn you if you are pushing yourself too hard.

Note card Activity: Do and Don't

Materials needed: Two 3 x 5 cards for each group member, prepared ahead of time with DO: written at the top of one card and DON'T: written at the top of the other card.

Purpose: This exercise helps members to consider and learn from their own experiences and the experiences of others. They will brainstorm a significant list of coping skills for dealing with caring for a loved one who is dying.

Directions: Hand out two 3 x 5 cards to each group member. One card says DO: at the top and the other says DON'T: at the top. Have each group member think about their own experiences so far in coping with their situations of caring for a loved one who is dying. Inevitably, each one has probably found some coping mechanisms that have worked positively for them (write on the DO card) and some that have not worked as well (write on the DON'T card). You can have them mix the cards up and share what is on the cards they get or have them share what is on their own cards. This can be decided depending on how open your group is. You can create a master list on a blackboard or a giant sheet of paper as the ideas are presented. Have group members positively reframe the DON'Ts into DOs. Discuss as you go, using the questions below as a general guideline.

Questions to consider/discuss: Have others tried this coping method? What was that experience like for each of you? What about each method listed was helpful or not helpful? What do you need to help you utilize one of these coping methods?

Task (optional): If you want your group to set a goal for coping, you can have them choose a new coping strategy and put it on the Action Plan Worksheet. Otherwise, just move into sharing what you know about coping strategies (See next page).

Danger Signs for Caregivers

1. You feel you're handling everything by yourself, yet what you're doing just isn't enough.
2. You don't seem to have any time or place to be alone.
3. You feel uncomfortable about going away, even for a few hours or a day.
4. There isn't anyone around to help, or so it seems.
5. Your family's getting impatient. They don't understand how hard this is.
6. Missing work or much of the time at work is spent worrying.
7. You think it would be selfish to think of yourself.
8. Feeling sad, lonely or anxious.
9. You're tired most of the time and dread getting up in the morning.
10. Getting angry at the person you're taking care of.
11. Feeling stretched economically, emotionally or physically.

Helpful Hints for Caregivers

1. Accept your feelings. All caregivers feel frustrated, guilty, overworked and alone. It's ok.
2. If you find yourself being negatively affected by responsibility, have the courage to change your care strategy. Spot early warning signs of trouble such as persistent irritability, sleep problems, depression, anxiety, and temper flareups.
3. Participate in support groups that will give you the time away from responsibilities as well as an opportunity to share with others in similar situations.
4. Recognize available options and be willing to exercise them.
5. Trust others with jobs and responsibilities, not only you can "do it right."
6. Prioritize tasks. Don't feel like everything must be done today.

Coping Strategies

1. Acknowledge your emotions as a common reaction in a challenging situation.
2. Talk about it. If you cannot talk about it, write about it.
 - a. Talking about your emotions helps you to let them go.
 - b. Talking reduces intensity.
 - c. Talking helps you define what you feel.
 - d. Talking clarifies issues in your mind.
 - e. Talking helps you feel more in control.
3. Exercise, eat well-balanced meals, and maintain a reasonably active schedule.
4. Avoid the use of drugs and alcohol as a method of coping with stress.
5. Don't take what is happening personally.
6. Keep the situation in perspective.
7. Realize that you cannot always control what is happening around you. You can, however, control your response to the situation. Don't take responsibility for events beyond your control.
8. Give yourself time to work through your feelings.
9. Identify and express your emotions.
10. Let yourself express your sadness by crying. This gives us an opportunity to receive support from others.
11. Postpone major life changes. Try to hold off on making any major changes, such as moving, remarrying, changing jobs or having another child. You should give yourself time to adjust to your loss.
12. Seek outside help when necessary. If your grief seems like it is too much to bear, seek professional assistance to help work through your grief. It's a sign of strength, not weakness, to seek help.

Sources:

- General Coping Strategies Following a Critical Incident (n.d.). Pine Rest CMHS pamphlet.
- Meuzelaar, C. (1989). Living through grief. *Pine Rest Today, Summer 1989*, 4-6.
- National Mental Health Association (2003). Coping With Loss. Retrieved from <http://www.nmha.org/infoctr/factsheets/42.cfm> on 2 April 03.

What Are You Feeling?

Understanding your feelings can be easier when you know ahead of time what to expect and what is commonly experienced as a reaction to the death of a loved one. Here is a timeline of what are common reactions to loss.

Immediate Reactions -- *the first few weeks following the death:*

Emotional

Shock
Relief
Release

Physical

Numbness
Shortness of breath
Heavy chest
Empty feeling

Behavioral

Denial
Disorientation
Crying
Listlessness

Later Reactions -- *after the shock wears off, you begin to feel your feelings once again:*

Emotional

Anger
Fear
Guilt
Panic
Loneliness
Depression

Physical

Chest pains
Lack of energy
Headaches
Fatigue
Vulnerability to illness
Tension

Behavioral

Over-reactive
Hyper-sensitive
Running
Sleeplessness
Isolation
Need to relive death

Adjustment -- *a time when you think you are going to "make it":*

Emotional

Taking responsibility
interests
Reconstructing your life

Physical

Looking forward
Doing things for oneself

Behavioral

Exploring new
Personal growth

Planning and Paper Work

This section focuses on the planning and paper work that is involved in losing a loved one. Advanced directives, check lists and useful steps are given in this section to help prepare for the planning and paperwork.

Five Wishes

Five Wishes is a living will that talks about a dying person's personal, emotional and spiritual needs, as well as medical wishes. This document, recognized as meeting the requirements of Michigan law, can be ordered by calling 1-888-5-WISHES or contacting *Aging with Dignity* by linking on to the website www.agingwithdignity.org.

In short, the *Five Wishes* document allows persons at the end of life and their loved ones to discuss what needs to happen when one is seriously ill. Wish One, *The Person I Want to Make Health Care Decisions for Me When I Can't Make Them for Myself*, allows one to designate a Health Care Proxy, and indicate the domains over which the proxy has authority. Wish Two, *My Wish for the Kind of Medical Treatment I Want or Don't Want*, offers opportunities for one to choose the type of care he or she would like to receive in certain situations, (i.e., close to death, in a coma and not expected to wake up or recover, permanent and severe brain damage and not expected to recover, etc). Wish Three, *My Wish for How Comfortable I Want to Be*, provides various personal care options. Wish Four, *My Wish for How I Want People to Treat Me*, provides various options for care provided by loved ones. Wish Five, *My Wish for What I Want My Loved Ones to Know*, provides options for one to check as well as open-ended questions for being remembered, memorial services, and any other concerns. The completed form must be notarized. Suggestions are given for making sure that others know of the completed form.

Planning a Funeral

Step 1: Draw up a will.

Regardless of how much or how little wealth you have, it's important to have a will unless you want the state to take over after you die. Have a lawyer draw one up (the fee depends on how complicated the will is).

Organize all the papers and important documents you'll need to take with you to the lawyer. Your will is an inventory of all that you own-real estate, bank accounts, stocks and bonds (if any), annuities, and life insurance.

List your personal property such as jewelry, paintings, and collectibles and specify who gets what. Maybe that special collection of coins to a favorite nephew, the heirloom jewelry to a sister, a bequest to your favorite charity.

Whatever, be clear about the distribution of your assets. But don't forget to list your liabilities-mortgage, loans, credit cards. You have covered everything. Short and sweet.

Step 2: Choose a funeral home and burial type

Decide on body disposition. Burial or cremation? If earth burial, a cemetery plot should be purchased; if above ground, a mausoleum crypt. If cremation is the choice, plan disposition of the ashes. Do you want them stored in a columbarium niche or buried? Maybe you prefer to have your ashes scattered?

Choose if a traditional funeral is desired and open or closed casket. Talk about whether or not to donate organs and tissues.

Step 3: Know where to find proper information

Know where to attain all necessary information after the loved one has died. For example: know where the will is, the desires of the loved one, and historical information about the loved one.

Preparation for Final Details

When your loved one dies, you will be experiencing many difficult emotions, but there are many documents to be collected and companies to be contacted. Knowledge of what needs to be done will keep this from being a shock and will help it be more manageable.

- 1. Collect the necessary papers.** A variety of documents are needed to file for benefits and take care of other financial matters. Refer to the checklist on the next page.
- 2. Contact insurance companies.** In addition to life insurance, check to see if other forms of insurance covered the deceased. Some loans, mortgages, and credit card accounts are covered by credit life insurance, which pays off account balances. Contact each insurance company about how to claim the policy benefits. If you can't find the individual policies among the deceased's papers, check the checkbook or paycheck stubs for premiums paid.
- 3. Notify Social Security.** You will need to notify the Social Security Administration if the deceased was already receiving Social Security. When applying for survivor's benefits, you will need to have birth, death, and marriage certificates, Social Security numbers, and a copy of the deceased's most recent federal income tax return.
- 4. Claim benefits.** Veterans, Social Security, and employee benefits may be available to you. Unions and other professional organizations provide benefits as well.
- 5. Begin probate.** Probate is the court-supervised process of paying the deceased's debts and distributing the estate to the rightful beneficiaries. Jointly owned property, property in trust, and assets with a designated beneficiary (life insurance, 401(k), pensions) do not go through the probate process. If the deceased did not have a will, state law will determine how the deceased's assets and property will be distributed to family members. The court will appoint a personal representative or the person named in the will as executor to manage the deceased's affairs. Contact the probate court in the state where the deceased lived for details.

Documents to collect

Death certificate – Available from your funeral director or county health department. Purchase at least a dozen certified copies of the death certificate. Most companies will want a certified copy, but use a photocopy when you can to save money.

Marriage certificate – Available from the county clerk where the marriage license was issued.

Birth certificates – For the deceased and any dependent children. Available at either the state or county public records offices where the person was born.

Social Security numbers – For the deceased, spouse, and dependent children.

Discharge papers – If the deceased was a veteran, you will need a copy of the discharge certificate. If you cannot find a copy, contact National Personnel Records Center, 9700 Page Boulevard, St. Louis, MO 63132-5200 (Send it to the attention of the branch in which the deceased served).

Original Will – The lawyer who wrote the will may have it. Or, it may be with the personal belongings of the deceased or in a safe deposit box. Some banks have special procedures before letting anyone into the safe deposit box.

List of property – A complete list of what the deceased owned including real estate, stocks, bonds, bank accounts, deeds, and personal property.

Recent income tax returns – If you cannot locate a copy of the most recent income tax return, you need to fill out IRS Form 4506. You will need to attach documentation that you are authorized to act on behalf of the deceased, such as letters from the probate court.

http://www.aarp.org/griefandloss/articles/70_c.html

My Friend, I Care

Don't tell me that you understand
Don't tell me that you know.
Don't tell me that I will survive,
How I will surely grow.

Don't tell me this is just a test,
That I am truly blessed,
That I am chosen for this task,
Apart from all the rest.

Don't come at me with answers
That can only come from me,
Don't tell me how my grief will pass
That I will soon be free.

Don't stand in pious judgment
Of the bounds I must untie,
Don't tell me how to suffer,
And don't tell me how to cry.

My life is filled with selfishness,
My pain is all I see,
But I need you, I need your love,
Unconditionally.

Accept me in my ups and downs,
I need someone to share,
Just hold my hand and let me cry,
And say, "My friend, I care."

Joanetta Hendel

Action Plan Worksheet

List three things that you want to accomplish upon leaving this group. Under each, list the steps necessary for completion of the goal.

1) _____

Step 1: _____

Step 2: _____

Step 3: _____

2) _____

Step 1: _____

Step 2: _____

Step 3: _____

3) _____

Step 1: _____

Step 2: _____

Step 3: _____

Evaluation

Of what was discussed today, what did you find was most helpful?

Is there anything that wasn't discussed that might have been helpful?

What did you find helpful about the activities? How could they have been improved?

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Post-Test

- 1) What is a common symptom one to two days to hours prior to death?
 - A. the patient may become agitated
 - B. the patients breathing stops
 - C. the patient may become very thirsty
 - D. The patient may have a surge of energy
- 2) What is the best response to take when the patient's arms and legs are cool to the touch?
 - A. always use an electric blanket.
 - B. use warm blankets to keep them from feeling too cold.
 - C. nothing, it's alright for them to be cool.
 - D. adding layers of clothing.
- 3) T / F Do you know of resources in the community that provide respite care?
- 4) T / F Talking about and writing about your emotions is a common and acceptable coping strategy?
- 5) T / F Only people with large amounts of money and assets need to write a will?
- 6) T / F Within the first few weeks following the death numbness is a common physical reaction.
- 8) On a scale of 1-5, with 1 being not at all comfortable and 5 being as comfortable as you could imagine being – How would you rate yourself with respect to your level of comfort in talking with your loved one about dying?

1 2 3 4 5

If you wanted to be more comfortable with this, what would be helpful?

- 8) On a scale of 1-5, with 1 being not at all comfortable and 5 being as comfortable as you could imagine being – How would you rate yourself with respect to your level of comfort in caring for your loved one who is dying?

1 2 3 4 5

If you wanted to be more comfortable with this, what would be helpful?

Additional Topics

On Being Alone: A Guide for the Newly Widowed

Losing a loved one is always traumatic. This is especially true with the death of a spouse. It is one of life's most profound losses. The transition from wife to widow, husband to widower, is a very real, painful, and personal phenomenon. The trauma of trying to adjust to this new identity while being besieged with a multitude of urgent questions and decisions can be overwhelming.

Here are several things to remember when faced with the death of your spouse. While they may seem simple, they are very important points to remember:

1. Give yourself permission to mourn.

Men and women both need to give themselves permission to mourn. Postponing a confrontation with your feelings by filling each day with frantic activity will only delay and compound the grief reaction. Denying your grief can be helpful in separating yourself from the pain. But, the agony is still there and it will stay there until you acknowledge it.

2. Be aware that you may experience a range of emotions.

Your reactions to death may cover a wide and confusing range of emotions (such as shock, numbness, anger, pain, and yearning). It may help to think of grief as clusters of reactions or fluid phases that overlap one another. Grief does not proceed in an orderly fashion any more than life itself does.

3. With effort, you can and you must overcome your grief.

One of the myths about mourning is that it has an ending point, that if you just wait long enough, it suddenly stops hurting. It doesn't. It requires work. More than time, bereavement takes effort to heal. Mourning is a natural and personal process that only you can pace. It cannot be rushed and it cannot happen without your participation.

4. When needed, find the strength to take action.

As a newly widowed person, there may be urgent financial and legal decisions you must make following the death of your spouse. You have just suffered an emotionally devastating event and the last thing you want to deal with is money matters. But money does matter, now and for your future, so try to do the best you can. Postpone, however, any decisions that can be put off until you feel better emotionally.

5. Work to tame your fears.

When the first impact of death wears off, you may feel you are losing control. This is a common part of the grieving process. Unlike mental illness, the strong feelings suffered during grief gradually and permanently disappear. Because you may experience a feeling of temporary instability, it's important to remember that you have the ability to cope. This is a time when much of your adjustment to widowhood takes place.

6. **In your own time, in your own way, you can say goodbye.**
The present, with all its pain and sorrow, is the only reality you have. Memories are very important, but they cannot be used as a shield against the present. At some point in your grieving, you will be ready to try to say goodbye.

7. **Stress can wreck havoc on your health.**
The effect of grief on our health is just beginning to be measured. While guarding your health can be among the least of your concerns during the throes of grief, you must work toward maintaining your health as soon as you feel able. This means beginning some form of regular exercise, getting proper nutrition, and reporting physical complaints to your doctor.

8. **If interested, consider employment, continuing education, or volunteer opportunities that match your needs and interests.**
Entering the job market after a long absence, or for the first time, can be one of the most challenging tasks that widowed persons encounter. If interested, look for ways to enhance, capitalize and build on the skills you've developed over the years. Don't be afraid to ask about employment opportunities whenever and wherever you can. Prepare well for your job search. If you do not need to return to work immediately, you may decide to go back to school or to contact Elderhostel, which offers educational opportunities in the U.S. and abroad. There are also volunteer opportunities that are meaningful and personally fulfilling in your community, which you may want to consider.

Bereavement – Guidelines for Growth

With the death of your loved one, your life has been irrevocably changed. A death experience can have strong and lasting effects. It can also open the way to new growth.

Because you have loved the person who died, you will, step by step, want to reinvest in life again. There are many ways to accomplish this. Perhaps these ideas will inspire you:

- Write. You may find keeping a journal will help to externalize your feelings. Or, you may want to write something influenced by or dedicated to the memory of the one you loved.
- Educate yourself about the grief process. The more you know, the more you will be able to help yourself. Funeral homes, hospices, and public libraries should be able to help you find reading material and help you connect to groups with other resources.
- Assist other bereaved people. Find an organization through which you can be a friend to the griever.
- Set a goal that is new and interests you.
- Take advantage of your religious affiliation, if you have one. If you have been inactive in matters of faith, this might be the time to become involved again. The Bible has much to say about sorrow. Old hymns are relevant.
- Exercise regularly. Return to your old program or start one as soon as possible. Depression can be lightened a little by the biochemical changes brought by exercise, and you will sleep better. An hour-long walk every day is ideal for many people.
- Recall the humorous times and laugh about them. Some will disapprove if you laugh “too soon,” but it’s not disrespectful. Remembering with laughter is helpful.
- Check on adult education and college programs available in your area. Choose a subject or skill you’ve always wanted to explore.
- Write down any goals you may have for the future – for example, getting a new job, taking a long-wished-for trip, continuing your education, or trying a new hobby.

You will reach a stage where you can accept your loss. You will be able to remember with less pain and focus on a future filled with hope. Whatever you do, do not waste your life in unproductive sorrow. The best memorial to a loved one is a full, growing life.

Remembering (Exercise)

Write a “memorable moment” in your life that you shared with your loved one that has died. Briefly describe why each was memorable.

1. Memorable holiday

2. Memorable trip

3. Memorable Party

4. Memorable meal

5. Memorable achievements

6. Memorable activity

SYMPTOMS OF STRESS

- **Fatigue** Tires easily. Previous level of energy may have diminished appreciably.
- **Insomnia** While sleep may be intensely desired, it is elusive once the person has retired for the evening. A similar condition is noted when one regularly awakens early with feelings of exhaustion or fright.
- **Inability to Concentrate** After watching TV, listening to a lecture, or even participating in a conversation, little content can be recalled.
- **Remorse** Usually as a result of guilt arising over either acts of commission or omission.
- **Indecision** Cannot make up their minds about anything. Even the simplest decisions seem too difficult to make.
- **Decreased affection** Unable to feel little affection towards those much loved in the past.
- **Anxiety** Often accompanied by feelings of tension, nervousness or fright. sometimes these feelings are so strong that they mask their underlying cause.
- **Irritability** Easily annoyed and impatient, particularly over trivial things.
- **Thoughts of suicide** Occasional or repeated thoughts of ending ones life to relieve the stress.
- **Concern about dying** Fearfulness of imminent death or a concern with both suicide and dying with increased frequency.

Helpful Tips To Relieving Stress

- Structure your time – keep busy
- You're normal and having normal reactions – don't label yourself crazy
- Talk to people – talk is the most healing medicine
- Reach out – people do care
- Maintain as normal a schedule as possible
- Spend time with others
- Keep a journal
- Do things that feel good to you
- Realize those around you are under stress too.
- Get plenty of rest
- Eat well-balanced and regular meals

For Family Members & Friends

- Listen carefully
- Offer your assistance and a listening ear if they have not asked for help
- Reassure them
- Help them with everyday tasks
- Give them some private time
- Don't take their anger or other feelings personally

(101 WAYS TO COPE WITH STRESS)

Caring for a Parent in your Home

Moving a parent into your home may not always be that easy. A number of situations and questions arise that need addressing. There are some issues that should be considered before the move is made.

Take into consideration:

Relationships:

- How will I talk to my mother about moving?
- How do my spouse and children feel about moving mother into our home and how will it change our lives together?
- What things will be easy for us to negotiate in living together and what things will be hard?
- What are the limits of my ability to care for mother at home and what if I have to put her in a nursing home?
- How will my siblings feel and how much help will they give me in caring for mother?
- Will her friends come to visit her at my house or will she be dependent on me for all her socializing?
- What are my needs for privacy and alone time?

Adapting Your Home:

- Where will mother sleep-in my daughter's room, convert the den, build an addition?
- What assistive devices do I need-grab bars in the bathroom, raised toilet seat, ramps, ect.?
- Does mother smoke or drink and will that be a problem for me?
- Does mother have a pet that will be coming with her and how will I cope with caring for it?

Money:

- What will financial arrangement be? Should I charge rent? Will I have expenses for her to cover?
- How will my siblings feel about the financial arrangement?
- Will my work situation have to change, and if so, how will I cover my bills?

Time:

- Will mother need care during the day, and if so, how will it be provided?
- How will I juggle my job, daycare responsibilities, marriage and taking care of mother?
- When in my day will I be able to make the phone calls needed to make arrangements for mother?
- When will I have time for myself?

Personal Care:

- How comfortable am I with helping mother bathe or changing an adult's diaper?
- Do I know what to expect over time as mother's condition changes?
- How is my health and will I be able to take care of myself as well as my mother?
- Am I willing to accept respite care to get a break?

Family Caregiver Alliance. FCA: Clearinghouse: Newsletter: Winter 2001. Retrieved from the World Wide Web on April 2, 2003. www.caregiver.org