

# *Completing Life's Journey*



*A Caregivers' Guide by:*



**Angela  
Hospice®**



**A**ngela Hospice has as its logo the butterfly. It is a symbol of hope and transformation and reminds us of how beautiful life is, even as we approach its end.

Each person's end-of-life journey is a unique experience. There are, however, certain common developments that occur as people progress through the dying process. These typically occur in three phases: the Stable Phase (p. 3), the Transitional Phase (p. 15), and the Active Phase (p. 27).

The following chapters will describe the characteristics of these phases. Our hope is that with an understanding of what to expect, you will be able to eliminate some of the fears and stress you may be feeling.

Please remember, we are always here for you and your loved one, and consider it a privilege to walk alongside you now.

Angela Hospice ♦ 14100 Newburgh Rd ♦ Livonia, MI 48154  
Toll Free (888) 464-2341 ♦ Fax (734) 779-6685 ♦ [www.AskForAngela.com](http://www.AskForAngela.com)

*Angela Hospice is a Catholic sponsored ministry in the Felician Franciscan tradition*



***Completing Life's Journey***  
**Chapter 1: Living with Change**





Someone you love is thought to be in the **Stable Phase** of the dying process. In the days ahead, there will be times of struggle. It will be important for you to take care of yourself as you learn how to care for your loved one.

All deaths involve physical, psychosocial, and spiritual preparation. The focus of hospice care is to provide physical, emotional, and spiritual comfort.

During this time, our goal at Angela Hospice is to assist your loved one to live each day to the fullest and to provide you with the support, information, and assistance that you need to grow through this experience.

This booklet is provided to help you understand the dying process and to suggest some actions you can take to support your loved one and take care of yourself.

## People often have less energy and sleep more.

### Things to know/things to do:

- Plan for periods of rest and activity. Schedule more intense activities during higher energy periods of the day.
- Break up high-energy tasks such as morning care into a series of shorter tasks with rest breaks in between (ex: Wash face, rest; dress, rest; brush teeth, rest; etc.).
- Schedule visits from family and friends at higher energy times and allow for periods of rest between visits.
- Frequent position changes (about every 2 hours) are necessary if your loved one is bed bound.
- Pillows help people stay in a side-lying position. Ask your nurse or aide to show you how to use pillows to position your family member.
- Your nurse can show you how to massage your family member's back/feet/legs with a favorite lotion or oil.
- You remain important even though your family member may not be able to tell you this. Your presence is the most important gift that you can give to your loved one.

## Weight loss may occur as eating habits change.

### Things to know/things to do:

- Offer food and fluids of choice.
- People sometimes do not have enough energy to eat or drink by themselves. Feeding may be necessary, but don't force foods if they are declined. Even favorite foods might not taste good. Sometimes people desire certain foods, and then refuse them. Try not to take this personally, it's just part of the disease process. Please speak to your nurse if this occurs.
- Some people begin to have trouble swallowing because of weakness involving the muscles in the throat. If you notice frequent coughing or choking, especially when drinking liquids, talk to your nurse. It may be necessary to thicken liquids or use other feeding techniques to make swallowing easier.
- Try using a straw or sippy cup if you observe problems with drinking.
- Keep lips moist with Chapstick or another lubricant and perform mouth care after meals. Sucking on hard candy, especially lemon drops, helps to keep the mouth moist and may improve comfort.
- Sometimes smells, particularly cooking, candles, and various perfumes cause discomfort. Try to eliminate or limit offending smells.

## The need for assistance with personal care activities increases.

### Things to know/things to do:

- Offer to stand by during personal care activities such as bathing, dressing, and toileting.
- Walking may become more difficult. If you notice problems with balance, weakness, or dizziness, provide assistance with walking or use a walker, cane, or wheelchair. Check with your nurse if you need one of these items.
- Keep walking paths clear, uncluttered, and well lit. Make sure slippers and shoes fit well.
- Keep walking aids such as canes within arm's reach.
- Place a stool or chair in the bathroom and other places used by your family member. Shower chairs and toilet seating aids are available at no charge through our agency.
- If getting to the bathroom is a problem, offer help on a regular basis (every 2-3 hours or so). Commodes are available through our agency for use next to the bed. Bedpans are also available.
- When in bed or a chair for long periods, help as needed with position changes every 2 hours or so.
- Keep all personal care items in one place that is easy to reach.
- Pay special attention to mouth care. If the mouth becomes sore and red, or has white patches in it, let the nurse know.

## Withdrawal from normal social activities may occur.

### Things to know/things to do:

- Respect choices regarding whether or not to have visitors. It is acceptable to limit the number of visitors and length of visits.
- Think about ways friends might support your family. Ask for help preparing meals, doing housework, or running errands.
- Sometimes well-meaning family or friends may question the end-of-life decisions that have been made. If this occurs and is problematic for you, please speak to your hospice team.
- Respect your loved one's right to privacy, but recognize how important your presence is to them.

*"It is not the end of the physical body that should worry us. Rather, our concern must be to live while we're alive - to release our inner selves from the spiritual death that comes with living behind a facade designed to conform to external definitions of who and what we are."*

*~ Elisabeth Kubler-Ross*

*"Whatever is needed will be provided."*

*~ Deepak Chopra*

*"'Tis dying I am doing - but I'm not afraid to know."*

*~ Emily Dickinson*

## Talking about dying.

### Things to know/things to do:

- People who are dying may be hesitant to discuss death with their families for fear of upsetting them. Others discuss death freely, and still others make it clear that they prefer not to discuss death at all.
- Some people use this time to prepare for their death by creating things for loved ones (i.e., memory books, videos, letters) or by making sure their affairs are in order. Some people like to help plan their own funeral or memorial service. Please contact your social worker or our spiritual care staff for help, if desired.
- Openly discussing death is hard for most of us, but when it happens, it can give families opportunities to bring up important issues, such as feelings of loss and grief, unfinished business, pain, spiritual needs, fear, or how to say goodbye.
- If you are not comfortable discussing death within your family and would like help to facilitate a discussion or discussions, please speak to your nurse, social worker, or a member of our spiritual care staff. We want to help.
- Pay special attention to listening carefully to each family member's concerns, allowing complete expression of feelings without being judgmental.

*“The Four Things that matter most - Please forgive me. I forgive you. Thank you. I love you.”*

*~ Ira Byock, MD*

## Some things to talk about:

1. Where does your loved one want to die, if there is a choice?
2. What kind of visitors, activities, and entertainment does your loved one want when he/she is tired?
3. What would your loved one like you to do for him/her?
4. How would your loved one like to be encouraged?
5. What bothers your loved one the most about what is happening?
6. What are your hopes and fears, and what are your loved one's hopes and fears?
7. What do each of you need to help each other?
8. Is there anything your loved one wants/needs to say or do that they will be sorry if they don't?
9. Do they want someone with them in the end?
10. Do they have funeral/memorial wishes?
11. Discuss the location of important papers (will, telephone numbers, email addresses, plans for disposition of belongings, bank account information, insurance information, bills, safe deposit boxes, any wishes for donations).
12. Encourage talk about personal achievements and what their life has meant.

## Care for the Caregiver: Taking Care of Yourself

Taking care of yourself helps your loved one. All things, including your body, will break under enough pressure. Here are some suggestions to try:

1. Give yourself permission to rest when you can.
2. Have a 'tool-box' for coping with stress:
  - a. Pause for a moment and take deep breaths
  - b. Have some quiet time for yourself
  - c. Listen to music
  - d. Ask us about respite care
  - e. Eat nutritional food
  - f. Walk with others, walk alone
  - g. Journal or write down your feelings
  - h. Talk about your feelings
  - i. Pray or meditate
  - j. Grieve your losses
3. Ask for help. Many people like to be supportive. It helps to let them know your specific needs (i.e., groceries, errands, laundry, picking up or taking children to activities, staying with your loved one while you take a break or do things you need to do).
4. Have trusted people to talk to and/or attend a support group.
5. Know that you are not alone.

*“There are all kinds of ties in one’s life, all kinds of friendships, loves, complexities, but there is only one person who one needs for dying. To have such a person is a great good fortune. To be that person, to have been such a person, is a heavy and blessed experience....Once at least, in each lifetime, we are meant to be a blessing to another.”*

*~ Gerda Lerner*

## Additional Resources

### Books:

Lynn, J. & Harrold, J. (1999). **Handbook for Mortals.** New York: Oxford University Press.

Doyle, D., Jeffery, D. & Colman, K. (Eds.) (2000). **Palliative Care in the Home.** London: Oxford University Press.

Vitez, M. (1998). **Final Choices: Seeking the Good Death.** Philadelphia: Camino Books.

Meyer, D. & Derr, P. (1998). **The Comfort of Home.** Portland, OR: CareTrust Publishing LLC.

Miller, J.E. (1997). **When You Know You're Dying.** Ft. Wayne, IN: Willowgreen.

Carson, A. (2001). **Circles of Care.** Boston: Shambhala Publications.

# Additional Resources

## World Wide Web:

### **Family Caregivers Online:**

This site is a service of the Area Agencies on Aging and provides education/resources for caregivers of older adults.

**<http://www.familycaregiversonline.com>**

### **Caring Connections:**

A program of the National Hospice and Palliative Care Organization, this is a national consumer and community engagement initiative to improve care at the end of life.

**<http://www.caringinfo.org>**

### **Dying Well:**

Dr. Ira Byock, long time palliative care physician and advocate for improved end-of-life care, and a past president of the American Academy of Hospice and Palliative Medicine, provides written resources and referrals to organizations, web sites and books to empower persons with life threatening illness and their families to live fully.

**[www.dyingwell.org](http://www.dyingwell.org)**

## **Additional Educational Resources Available Through Angela Hospice**

- Managing fatigue
- Information about how to use any of the medical equipment we provide
- Myths about narcotics
- Positioning for comfort
- How to manage nausea and other uncomfortable symptoms
- And many other topics. If you have a question, just ask us!



***Completing Life's Journey***  
**Chapter 2: Transitions**





**A**s disease progresses, the body weakens and slows. Because of these changes, we have found that our patients' needs for support change. We call this time the **Transitional Phase**.

This phase usually lasts from one to a few weeks. As your loved one's condition declines, you will see the natural slowing of body systems. Your loved one will need more assistance with personal care. *They will sleep more, eat less, become weaker, and perhaps be less communicative.*

The focus of hospice care is to provide comfort. As you learn how to support your loved one, it is our hope that the symbol of the butterfly will continue to remind you that these times of struggle and change are also a time of transformation.

## As weakness increases, falls and other safety concerns become a real risk.

### Things to know/things to do:

- **ALWAYS provide assistance with walking.** Most falls are due to increasing weakness and lack of supervision. Many dying patients don't realize that they are as weak as they are and often make the mistake of trying to walk without help. Be sure to use walkers, canes, etc., if needed; and if you find that you have to bear more than 50% of the weight, ask another person for help. Discuss activity levels and support with your nurse.
- **Close monitoring is important.** Use friends, other family members or hospice volunteers to assist you. Personal sound monitors are often helpful. Supervise activities that involve risk, such as smoking.
- Check bedside areas for sharp corners and pad them to prevent injury in case of a fall.

*“May sorrow show me the way to compassion.  
May I come to recognize the gift of my loved one’s  
death by opening my ear of compassion.  
May I realize grace in the midst of suffering.  
May this experience in some way be a blessing for me.  
May loving-kindness sustain me.  
May love fill and heal my body and mind.  
May I be peaceful and let go of expectations.  
May I find peace and strength that I may use  
my resources to help others.  
May I receive the love and compassion of others.  
May all those who are grieving be released from their suffering.  
May I offer love, knowing that I cannot control the course  
of life, suffering, or death.”*

*~ A Buddhist prayer for transcendence*

## Sleep increases, often to most of the day.

### Things to know/things to do:

- People who are in this transitional phase can be difficult to arouse. Waking is not necessary except to give medications scheduled around the clock for pain or other symptom management. To avoid a pain or other symptom crisis, scheduled medicines should usually be given. If you are having difficulty waking up your loved one to give medication, speak to your nurse.
- Some people may have trouble communicating their discomfort. If this is the case, it is important to look at body language for clues that pain or discomfort is present. These may include facial grimacing, squirming or jerking, crying, clenched jaw or hands, furrowed brow, or tearing.
- If your loved one experiences pain with turning, bathing, or other care activities, you may give pain medication 15 to 20 minutes before the activity to decrease the discomfort.
- Pillows help people stay in a side-lying position. Ask your nurse or aide to show you how to use pillows for positioning.

*“...stay with me, even as I am falling away from you.”  
~ From Free Fall*

**Most people stop eating or drinking completely, or eat very small amounts. There may be problems swallowing or little interest in food or drink.**

Things to know/things to do:

- Do not force your family member to take in food or fluids, but make them available. As patients decline, the digestive system slows and is not able to digest food normally. The kidneys may begin to shut down, and drink will cause congestion in the lungs and swelling under the skin. Intravenous (IV) fluids are not recommended for this reason.
- If your family member continues to express an interest in eating, but coughs and chokes when trying to eat or drink, speak with your nurse.
- Try using a straw, sippy cup, or a syringe (available from your nurse) if managing a glass becomes difficult.
- Position the head of the bed at a 45-degree angle when offering food or drink.
- Keep lips moist with Chapstick or lubricant and perform mouth care frequently. We can provide swabs that are convenient to clean secretions and keep the mouth moist. A swab soaked in water, ginger ale, or a favorite fluid could be used.

## Personal care will need to be given.

### Things to know/things to do:

- Check bedding regularly to make sure it is clean, dry, and not wrinkled.
- Using a turning sheet or blanket will make it much easier to reposition your loved one. Your nurse or aide can demonstrate this if necessary.
- Offer toileting assistance on a regular basis (every 3-4 hours or so). Commodes are available through our agency for use next to the bed. Bedpans are also available. **Be sure to provide assistance with toileting.**
- If you use a bedpan, place a blue pad beneath it to absorb spills. Make sure to remove it when done.
- Provide a bed bath as needed for comfort. Please let us know if you would like us to teach you how to do this. We also have aide services available to help you. It is helpful to apply lotion to moisturize the skin after the bath.
- If blue pads are used, cover them with bedding or a turning sheet. Perspiration can make the blue pad stick to the skin, causing discomfort and increasing the chance of skin breakdown.

*"I get by with a little help from my friends."*

*~ John Lennon*

**Incontinence or ‘accidents’ may occur as control of bowel and bladder function decreases. Urine volume lessens. Urine becomes dark and concentrated.**

Things to know/things to do:

- It is important to try to keep the private area as clean and dry as possible to prevent skin breakdown. We will teach you how to provide this care and will recommend helpful products, if necessary.
- Be vigilant about checking for incontinence about every two hours.
- The urine output may gradually decrease and have a strong odor and dark color.
- It may be difficult to keep your loved one clean and dry at all times. In these cases, your nurse may suggest the use of a Foley catheter to drain urine. If one is used, we will show you how to care for the catheter and empty the drainage bag.
- Constipation may become a problem. Let the hospice nurse know if there has been no BM for 3 days.

*“When you were born, you cried and the world rejoiced.... When you die the world cries and you rejoice.”*

*~ Native American Proverb*

## **The risk of skin breakdown is higher now.**

### Things to know\things to do:

- The risk of skin breakdown increases as people move, eat, and drink less.
- Reposition your loved one every 2-4 hours if he/she is not doing it alone. Bony areas such as heels, the lower back, and the elbows are more likely to break down, so special attention should be made to relieve pressure in these areas. Obtain extra pillows or other special pressure relief supplies from your nurse if you need them.
- Use care when using blue pads. Use a folded sheet between your family member's skin and the blue pad to help keep the air flowing and the skin intact.
- Provide a bed bath to help keep the skin moist and apply lotion to the entire body.
- Use a moisture barrier ointment such as Calmoseptine or Desitin when providing care to private areas.
- If you observe a rash, any sores, or reddened areas, please let your nurse know as soon as possible.
- We have nursing assistants available if you would like help with personal care.

## Your loved one may be working through unresolved spiritual and emotional issues.

### Things to know\things to do:

- Listen carefully to concerns and wishes and help reconcile personal, spiritual, or emotional relationships.
- Unusual statements, gestures, or requests sometimes occur. Dying patients may say something out of character that may indicate they are ready to say goodbye (ex: “I have to catch a plane” or “I’m going home”). This is an important time to give permission to your loved one to die if you are able to do so.
- When you are ready, saying goodbye is your final gift of love. It often helps to make the final release a little less difficult.
- Request the support of your Angela Hospice social worker or spiritual care provider if needed.

*“Death is simply a shedding of the physical body like the butterfly shedding its cocoon. It is a transition to a higher state of consciousness where you continue to perceive, to understand, to laugh, and to be able to grow.”*

*~ Elisabeth Kubler-Ross*

## Sometimes, people who are dying appear to be confused, or say things that don't seem to make sense.

### Things to know\things to do:

- Always identify yourself when you approach your loved one. Describe what you are planning to do before you provide care. Keep it simple.
- Don't leave a confused person alone when they are awake.
- Speech may be difficult to understand. Try to stay open and accepting.
- A natural part of the dying process is to do a life review. Your family member may communicate with people who have already died or may see people or places not visible to others. Do not try to contradict, explain away, belittle, or argue about what the person says they have seen or heard.

### The Butterfly

*It wavered there over my head  
Seeming so light in the summer wind  
I lifted up my hand and  
It lit upon my finger  
Slowly flapping wings together  
It looked at me for what seemed forever  
I smiled, reached deep and  
Found all those cherished memories  
As it flew away through the waning dusk  
I knew we had said "Hello"  
Once again*

~ Sandy Whalen, from [www.dying.about.com](http://www.dying.about.com)

## Additional Resources

### Books:

Byock, I. (2004). **The Four Things that Matter Most.** New York: Simon and Schuster.

Smith, D. (1997). **Hospice-Proven Techniques for the Body and Soul.** Hampshire, England: MacMillan.

Fanos, J. (1996). **Sibling Loss.** Mahwah, NJ: Laurence Erlbaum Associates.

Harwell, A. (1995). **Ready to Live, Prepared to Die.** Wheaton, IL: Harold Shaw Publishers.

### World Wide Web:

#### **Growth House:**

Growth House is an online resource to education/ resources for life-threatening illness and end of life care.

**[www.growthhouse.org](http://www.growthhouse.org)**

#### **Hospice on the net:**

This not-for-profit online resource provides education/resources for hospice patients and families.

**[www.hospicenet.org](http://www.hospicenet.org)**

## **Additional Educational Resources Available Through Angela Hospice**

- Caring for caregivers: Taking care of yourself while taking care of someone who is dying
- Good skin care and pressure sore prevention
- How to manage difficult symptoms, such as pain, anxiety, or nausea
- How to manage eating and drinking difficulties
- How to manage breathing problems
- And many other topics. If you have a question, just ask us!



***Completing Life's Journey***  
**Chapter 3: Letting Go**





Each person's death is a unique experience, but all deaths involve physical, psychosocial and spiritual preparation. As your loved one is transformed to leave this life, you as a caregiver are also transformed. You grow and change as you learn to do things you never thought you could do.

As your loved one's death approaches, you will see the normal, natural slowing of body systems. The **Active Phase** of dying usually lasts a few days. Your loved one may be unconscious and require total physical care.

During this time, our goal at Angela Hospice is to assist your loved one to have a comfortable, dignified, and peaceful death, and to provide you with the support and information you need to care for him or her.

## You will need to provide personal care.

### Things to know/things to do:

- Check bedding regularly to make sure it is clean, dry, and not wrinkled.
- Use a turning sheet or blanket to make it easier to reposition your loved one. Ask your nurse or aide if you need help.
- Most people require incontinence products (diapers) and need to be cleaned each time they become wet or soiled. We can teach you how to provide this care if you are unsure about what to do.
- If blue pads are used, cover them with bedding or a turning sheet. Perspiration can make the blue pad stick to the skin, causing discomfort and increasing the chance of skin breakdown.
- Provide a bed bath as needed. We can teach you how to do this, and also have aide services available to help you. If you are having problems providing a daily bath, please let us know.

*“Death is not extinguishing the light. It is putting out the lamp because dawn has come.”*

*~ Tagore*

## The risk of skin breakdown continues to be very high.

### Things to know/things to do:

- When people cannot reposition themselves and are not eating or drinking, the risk of skin breakdown is high.
- Reposition your loved one every 2-4 hours. Bony areas such as heels, elbows, the spine, and lower back are more likely to break down, so special attention should be made to relieve pressure in these areas. Obtain extra pillows or request other special pressure relief supplies from your nurse if you need them.
- If repositioning causes discomfort at this stage, frequent turning may no longer be necessary. Giving pain medications 15 to 20 minutes before turning may help. You may need to turn your loved one on one side with the head elevated to make breathing more comfortable. If you find that turning causes severe discomfort, discuss this with your nurse.
- If you observe a rash, any sores, or reddened areas, please let your nurse know as soon as possible.

*“It is as natural to die as be born.”*

*~ Francis Bacon*

## The urine will decrease in amount and become dark and concentrated with a strong odor.

### Things to know/things to do:

- The amount, color, or smell of the urine will change. The amount of urine will decrease or stop. It may have a strong odor and dark color. Let your nurse know what you are observing. If you have any questions, please ask.
- Be vigilant about checking for incontinence at least every 2 hours.
- It is important to try to keep the private area as clean and dry as possible to prevent skin breakdown. We will teach you how to provide such care and will recommend incontinence products, if necessary.
- It may be difficult to keep your family member clean and dry at all times. In these cases, it might be appropriate to use a Foley catheter to drain urine. If one is used, we will show you how to care for the catheter and empty the drainage bag.
- Let the hospice nurse know if there has been no BM for 3 days.

*“Just when the caterpillar thought the world was over, it became a butterfly.”*

*~ Anonymous*

## Usually, people have little or no food or fluid intake.

### Things to know/things to do:

- Do not try to force food or fluids.
- Small chips of ice, frozen Gatorade, or a favorite juice enjoyed in the past may be refreshing. Do not offer these things if your family member is non-responsive.
- Sponge toothettes may help keep the mouth and lips moist and comfortable. Your nurse can provide toothettes and show you how to use them.
- Apply a moisturizer to the lips to help keep them moist.

*“May I let go of guilt and resentment.*

*May I forgive myself for mistakes made and things left undone.*

*May I forgive and be forgiven.*

*May I forgive myself for not meeting my loved ones’ needs.*

*May I accept my human limitations with compassion.”*

*~ A prayer of forgiveness from [www.upaya.org](http://www.upaya.org)*

## Restlessness sometimes occurs.

### Things to know/things to do:

- You may notice restless movements or attempts to call out or speak to deceased friends or relatives. Do not try to correct, restrain or interfere with these actions unless they result in an unsafe situation.
- Sometimes people are restless because they are uncomfortable. Try to determine whether pain or other uncomfortable symptoms (anxiety, nausea, constipation, etc.) are causing the restlessness.
- **Do not leave a restless person alone.**
- Some medications are available that are useful for managing restlessness. Please let your nurse know if your loved one appears uncomfortable because of restlessness.
- Keep the side rails up on the bed (if side rails are present), but be aware that the presence of a side rail does not prevent an injury. If a side rail is needed for safety, someone should also be present. Sometimes side rails need to be padded to prevent injury. In addition to the pads that we have available, blankets and towels can be used to soften side rails.

*“Love is the only thing we can carry with us when we go, and it makes the end so easy.”*

*~ Louisa May Alcott*

## Vital signs may become unstable.

### Things to know/things to do:

- You may notice an increased pulse, or a fast or slow rate of breathing. Blood pressure also decreases. There are medications available to help with fast breathing.
- In most cases, oxygen won't be helpful and is not necessary.
- Many people develop a fever as they near death. Tylenol suppositories are available to reduce the fever and associated discomfort. A cool washcloth on the forehead may be soothing.

**As death approaches, the skin becomes cool, and fingers and other extremities may take on a bluish color that might come and go. Body temperature may fluctuate between hot and cold.**

### Things to know/things to do:

- Keep the room at a comfortable temperature. If you notice that your loved one is sweating or feels too warm, remove some bedding. Likewise, if you notice cool body temperatures, add some bedding. Do not use electric blankets.

*“Death ends a life, but it does not end a relationship.”  
~ Dennis Klauss*

## **Breathing changes. Some people have breathing difficulties or may make rattling sounds with each breath.**

### Things to know\things to do:

- Noisy breathing (rattling sounds) is usually caused by air passing by secretions gathered in the throat. These secretions do not cause difficulty breathing. Breathing is usually easy, although it is noisy.
- Suctioning and oxygen may or may not be necessary. Often, turning a person to the side or raising the head of the bed is enough to clear away excess secretions. There are also medications available that may help. Ask your nurse for more information.
- You may notice periods when breathing stops then starts up again. This is called apnea. These periods can sometimes last as long as 20 seconds or more.
- Often at this time, the breath has a strong, fruity odor that does not go away with mouth care.
- Mouth breathing is common, causing dryness. Use a moistened swab or washcloth to keep the mouth and lips moist and clean. Applying a lubricant to the lips also increases comfort.
- Continue to speak to your loved one. Reassure them that they are safe and that you are there.
- If your family member appears uncomfortable because of breathing problems, please call our office. We are available 24 hours per day.

## Most people eventually become unresponsive.

### Things to know\things to do:

- Your presence is important. Continue to touch and speak to your family member, even though there may be no response. Your family member may still be able to hear and understand what you are saying.
- Announce your presence when approaching your loved one, even if he/she appears not to respond. Explain things you are about to do before you start.
- There is no need to increase the volume of your voice when speaking. Speak softly and clearly.
- Speak truthfully to your family member. Say whatever you need to say.
- When breathing stops, it is not an emergency. You may want to spend some time with your loved one, speak with them or bathe them. When you are ready, call your nurse and they will assist you with the final arrangements.

*“I wanted a perfect ending. Now I’ve learned that some poems don’t rhyme and some stories don’t have a clear beginning, middle and end. Life is about not knowing, having to change, taking the moment and making the best of it, without knowing what’s going to happen next. Delicious ambiguity.”*

*~ Gilda Radner, just before her death*

## Additional Resources

### Books:

Kubler-Ross, E. (1997). **The Wheel of Life: A Memoir of Living and Dying**. New York: Scribner.

Miller, J.E. (1997). **The One You Love is Dying**. Ft. Wayne, IN: Willowgreen Publishing.

Nye, M.B. (1978). **But I Never Thought He'd Die: Practical Help for Widows**. Philadelphia: Westminster Press.

Remen (1996). **Kitchen Table Wisdom: Stories That Heal**. New York: Riverhead Books.

### World Wide Web:

#### **GriefNet:**

This web-based non-profit organization gathers and disseminates information on death and dying, grief and bereavement, and major loss.

**<http://www.griefnet.org>**

#### **On Our Own Terms:**

This web-based resource and education site was created after Bill Moyers presented the PBS series "On Our Own Terms: Moyers on Dying."

**<http://www.pbs.org/wnet/onourown/terms>**

#### **Dying Well:**

Dr. Ira Byock, long time palliative care physician and advocate for improved end-of-life care, and a past president of the American Academy of Hospice and Palliative Medicine, provides written resources and referrals to organizations, websites and books to empower persons with life threatening illness and their families to live fully.

**<http://www.dyingwell.org>**

## **Additional Educational Resources Available Through Angela Hospice**

- Information about the medications your family member is taking
- Information about how to use any of the medical equipment we provide
- Grieving and loss information
- How to choose a funeral home
- How to discuss death and dying with children and adolescents





**Your Case Manager:** \_\_\_\_\_  
If you have questions, please contact us at (888) 464-2341.

**W**e at Angela Hospice thank you for the opportunity and privilege of being with your family during this time.

Thomas Moore said, "At every moment, we are... an emerging butterfly." May this image stay with you and give you hope and strength through this difficult journey.

This pamphlet was developed by a team of nurses at Angela Hospice Home Care for the use of our patients and their families. Illustrations by Suzanne Haskew, Muckybottom Studio.

©2004