



Asking for Help

“Journeys” – A Series of Seven Booklets on Dying At Home, Booklet #3

Dying is a difficult journey that everyone will take someday. However, the burden of dying can be eased with the love and support of family and friends. By accepting their offers of help, you show them that their gifts are special and you gain precious time and energy to experience the important moments in your remaining days. Here are some suggestions to help others help you:

- *You have to ask.* Most people feel uncomfortable about asking for help. Family and friends will probably appreciate hearing from you. Some people may be reluctant to impose on your privacy by offering to do things for you. Open, honest communication of your needs and expectations is the best way to avoid misunderstandings.
- *Be specific.* When you accept someone’s help, be specific about your needs and wishes. Let others know what you need. Tell them when their help would be most useful. If necessary, say exactly how you would like the job done. We all like to do things our own way, so if having someone else perform a certain task would cause you stress, kindly decline that offer. Illness and dying are stressful enough – don’t add to your grief unnecessarily. Make a suggestion: *“Thanks for your offer, but I prefer to do that myself. However, I could really use help with...”*
- *Accept offers.* Accept offers of help without feeling guilty or obligated. True friendship comes freely from the heart and soul. Consider – if you were a friend wanting to help, how would you feel if your offer were declined.
- *Be selective.* When people are very ill or dying, their energy level declines. It usually becomes more difficult to complete tasks. You may find it necessary to rest before you finish what you started to do. This is not unusual. Decide what is most important to you and spend your valuable energy on that task. Leave those tasks you don’t enjoy for family members and friends who are offering help.
- *Communicate.* Let others know your thoughts and feelings. Share your experiences and fears. Try to avoid expecting others to know what you are thinking or feeling. You will be disappointed when they can’t read your mind. Your family members and friends are experiencing your journey for the first time too, so give them some directions along the way.
- *Organize.* Make a list of things that you need or would like help with. When you make your list, fill in the person’s name beside each task, along with the time and day you would like it done, so that anyone can look at the list and know what to do. The finished list can be hung on the fridge or in a common place to help everyone in your life maintain your household schedule. Update the list as often as necessary to suit your wishes and needs.

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- *Delegate.* Hand off routine duties such as running errands, paying bills, cleaning the house, washing dishes, shopping for groceries, picking up supplies, cooking meals, getting the mail, doing yard work, laundry and ironing.
- *Create a loop.* Accept an offered home-cooked meal on appointment days. Accept help with housework on those days so when you return you can enjoy a nap in a clean, quiet house without the noise of the vacuum. Try to schedule appointments and visits on different days so you don't wear yourself out. Too much activity in one day can cause unnecessary stress and fatigue. Ask friends to cancel a visit or change plans to suit your needs. As friends, they will understand your feelings.
- *Be considerate.* No doctor, nurse or member of the hospice palliative care team works 24-hours a day, seven days a week and neither can your caregiver. The people in your support network will need a break once in a while too. Everyone closely involved with your life and your care will experience stress. Try to be aware of your caregiver's needs as well as your own. Talk about feelings, needs, fears and expectations.
- ◆ *Share the journey.* Coming to terms with your grief on this final journey is particularly difficult.

As one author has put it: *“Grieving involves our physical, emotional and spiritual being. There may be a struggle with appetite, sleep, weakness, shortness of breath, fear, disbelief, disorganization, anger, forgetfulness, lack of desire to do anything, relief, guilt, anguish, yearning, helplessness, intense sadness, unexpected and sometimes uncontrollable crying and irritability.”*

However, you are not alone. You may find comfort in sharing your emotions with those who are supporting you on this journey.

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Approaching Death

Changes Associated With Dying

Death is a unique experience for everyone. People die in their own time, in their own way and often, people will die the same way in which they have lived.

A person who has always shared their feelings is likely to continue to do so throughout the dying process. Whereas those who have kept their feelings to themselves, are likely to continue to do so as they approach death. A person who has been very private and independent will approach the end of their lives in the same way.

There are no “light bulb” moments that magically turn difficult people into caring, thoughtful people. This is not the time to try and change people, but to give full acceptance, support and comfort.

There is no right or wrong way to die. Each person and family is unique and needs to do things in their own way. The dying process for each person and family will be different and right for them.

Dying happens to a whole person – physically, mentally, emotionally and spiritually – over a period of time.

Physical Changes

The body is shutting down and the physical changes that occur have to do with circulation, metabolism, breathing, lung secretions, bladder, bowels, etc. What is abnormal when someone is well, is normal when someone is dying. Usually the process of shutting down is an orderly and progressive series of physical changes. These are not considered medical emergencies that require invasive interventions.

Mental Changes

Mental activity may decrease during the dying process. People may experience periods of restlessness, confusion, disorientation, increased sleepiness or unresponsiveness.

Emotional Changes

Dying people begin to withdraw and detach from the outside world, pulling inward as death nears. This is a process of letting go.

Spiritual Changes

Dying people often need to resolve or reconcile outstanding issues or unfinished business prior to death and to say goodbye to loved ones.

Signs of Dying

“Preparing for Approaching Death” Reference: Hospice Net – www.hospicenet.org

As death gets closer, family members may observe more signs of the body shutting down. The following are some of the signs that death may be near. No one can predict with any certainty when death will occur. Like birth, death comes in its own way, at its own time.

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Coolness

The person's hands and arms, feet and then legs may be increasingly cool to the touch and at the same time the color of the skin may change. This is a normal indication that the circulation of blood is decreasing to the body's extremities and being reserved for the most vital organs. Eventually the skin will become mottled (purplish discoloration) as the person approaches death.

- ◆ Keep your loved one warm with a blanket, but do not use one that is electric.

Sleeping

A dying person spends an increasing amount of time sleeping and may at times be unresponsive and difficult to arouse. This is normal.

- ◆ Sit with your loved one, hold their hand.
- ◆ Assume your loved one can hear – hearing is the last of the senses to be lost. Speak softly and naturally to your loved one. Tell them the things you want them to hear. Play their favorite music.

Congestion

A dying person may have gurgling and rattling sounds coming from their chest. This normal change is due to the decrease of fluid intake and an inability to cough up normal secretions. Suctioning usually only increases the secretions and causes sharp discomfort.

- ◆ Gently turn the person's head to the side and allow gravity to drain the secretions.
- ◆ Your physician can also prescribe a medication to dry up the secretions.

Breathing

The dying person's breathing pattern will change. A particular pattern consists of breathing irregularly – shallow breaths with periods of no breathing of five to thirty seconds and up to a full minute. This is called Cheyne-Stokes breathing. This does not cause distress to the patient.

- ◆ Elevate the head and/or turn your loved one on their side. Hold their hand, speak gently.

Urine Output

The dying person's urine output will decrease and become dark in colour. Incontinence may become a problem. Your loved one may need a catheter to keep them clean.

Restlessness

Due to the progression of disease, sometimes people become delirious and hallucinate. This is called pre-death restlessness.

When death is near, you may be feeling many things – tremendous sadness, fear and anxiety and even relief. Your journey has no doubt been stressful and challenging. Allow yourself to feel a range of feelings and emotions. There is no right or wrong way to cope with the death of a loved one.

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Saying Goodbye

Knowing someone you love is approaching death provides an opportunity to express your true feelings. It's a time when you can say, "thank you", "I love you", "forgive me", "I forgive you", and "good bye".

A dying person will try to hold on, even though it brings prolonged discomfort, in order to be sure those who are going to be left behind will be all right. You may need to give your loved one permission to let go and assure them that you will be all right. As difficult as this may be, it is one of the greatest gifts you have to give your loved one at this time.

When your loved one is ready to die and you are able to let go, then is the time to say goodbye. Saying goodbye is your final gift. It achieves closure and makes the final release possible. It may be helpful to lay in bed with or hold your loved one, or to take his or her hand and then say everything you need to say.

It may be as simple as saying, I love you. It may include recounting favorite memories, places and activities you shared. It may include saying, I'm sorry for whatever I contributed to any tension or difficulties in our relationship. It may also include saying, Thank you for...

Tears are a normal and natural part of saying Goodbye. Tears do not need to be hidden from your loved one or apologized for. Tears express your love and help you to let go.

At The Time Of Death

The signs of death include:

- ◆ Breathing stops
- ◆ Heartbeat stops
- ◆ You cannot rouse the person
- ◆ The eyelids may be partially open in a fixed state
- ◆ The mouth may fall open as the jaw relaxes
- ◆ The bowel or bladder may empty

This is an expected death – it is not an emergency. Do not call the police, the ambulance or 911. If you are in the hospital, notify the nursing staff. If you are at home, call your Extra Mural Nurse or the funeral home.

Remember, nothing must be done immediately. The body does not need to be moved until you are ready. This is a special and sacred moment - a time for peace, sadness, relief and reflection. Talk to the spirit, if you wish. Hug your loved one. Take deep breaths. Sit down. Say a prayer or have a moment of silence. Call others who would want to know and be there with you. This may be your only private time with your loved one to say goodbye and begin the grieving process.

After The Death

Caring for a loved one who is dying is very difficult. Take comfort in the fact that you have braved a difficult journey. Know that the love and support you provided to your loved one brought much needed comfort and helped to make a difficult life experience both manageable and meaningful. You have indeed been courageous and provided the greatest gift of love.

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You are now on another journey – grieving the loss of your loved one and finding your way back to living.

Grieving is a natural response to loss – a process of healing a broken heart. It will affect you totally – physically, emotionally, psychologically and spiritually and last much longer than society recognizes.

As you grieve the loss of your loved one, you will experience many ups and downs. You will be tempted to run away from grief or to find a simple solution that will magically end your pain. It takes great courage to cope with loss and begin to embrace life again.

Just as Hospice has been with you during the life and death of your loved one, Hospice is here to help you cope with your grief journey.

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