



## **Family Caregiving at Life's End**



*Recognizing your strengths in  
caring for family and friends*





## Family Caregiving at Life's End

Dying is a natural part of life, and may be filled with mixed emotions and times of reflection for both the dying person and family caregiver.

Providing care for someone who is dying can be personally rewarding even in the midst of balancing the tasks of caregiving.

If you are a family caregiver for someone in the final stages of life, this information will help you to care well for yourself and your family member.

The signs and symptoms of the dying process found in this booklet serve only as a guideline. It begins with what you may expect when your family member has more than three months to live. Not all individuals will experience all symptoms, and the signs and symptoms may not occur in sequence. If you have questions about the changing signs or symptoms in your family member, contact your health care provider.

## Greater Than Three Months

Pace yourself! You may provide care to your family member for a short time or a very long time.

It may seem important that you provide all of the care yourself, but it is okay and at times necessary to ask for help. When people offer help, accept the offer and suggest specific things they can do. At this time, seek out community resources that make it easier to help the person you are caring for, including hospice care.

Care well for yourself and look for the positive experiences in caring for your family member. Caregiving at life's end is probably the most important thing you will ever do.

## What You May Expect in Your Family Member

- Putting affairs in order
- Up and about but weak
- Alert and oriented
- Maintains control

### One to Three Months

Before your family member becomes more weak or withdrawn, you may want to offer these four “gifts,” which are known to bring comfort, reassurance, hope and peace of mind:

- I love you
- I forgive you, and ask your forgiveness
- I thank you
- I let you go

Be clear with others about what is helpful to you and your family member:

- When you would like phone calls
- How long visitors should stay
- Your preferences around “dropping in”

Caregiving at life’s end includes making decisions, some of which may be very difficult. Consider holding a family meeting to involve others in the decision-making.

Care well for yourself. What you are doing is very valuable, but not easy.

- Withdrawing from the world and people
- Internalizing and becoming less communicative
- Increasing sleep
- Decreasing food intake with appetite changes
- Increasing weakness
- Swelling (edema) of the legs



### One to Three Weeks

Arrange enough physical help to allow yourself to be emotionally present. Other people can change your family member's sheets or bring them ice chips, but only you can share precious memories with them or give them the hugs and kisses that truly comfort.

Prepare internally for a time ahead when daily routines of eating, sleeping, working might change radically. The dying process is a very powerful experience on all levels and there can be a "roller coaster" effect that cannot be altered, only experienced.

Consider the idea of "sitting vigil" as death approaches by maintaining a presence at bedside during the final hours of life. Enlist visits from special family and friends and create an environment of peace and comfort by gathering together special music, photo albums, readings, or prayers.

Care well for yourself. This can be tough going.

- Increasing weakness
- Sleeping most of the time but responding
- Increasing confusion – talking with the unseen
- Picking at clothing and increased agitation
- Body temperature changes between hot and cold
- Skin color changes: pale yellowish pallor (skin tone), flushed with fever, bluish with cold
- Breathing changes with increased congestion
- Eating and drinking very little

### Days or Hours

You are entering a very special time, one that you will remember for the rest of your life.

Begin a sitting vigil, if this is your choice, by calling in those who will be present with you.

Be prepared to “hurry up and wait” (or vice versa). The dying process keeps its own rhythm, and can be much longer or shorter than anticipated.

If you find yourself at the bedside unsure of what to do, trust that simple waiting is enough and try one or more of these:

- Read out loud
- Share memories – a dying person can often hear long after they have ceased speaking or moving, and your voice (and laughter) can be very soothing
- Sing songs or play soft music
- Breathe with your family member; follow their inhalation and exhalation

Care well for yourself. You are approaching the end of a journey.

- Intensification of the One to Three Week signs
- Bed bound
- Surge of energy
- Restlessness and increased agitation
- Irregular breathing patterns including pauses in breathing (apnea)
- Congestion
- Glazed, staring eyes that may be open or semi-open
- Hands and feet bluish with blotchy coloring of knees, ankles and elbows
- Increased peacefulness
- Less responsive with decreased verbal response
- Decreased urine output with some incontinence

### Minutes & Time of Death

Try to let go of any intentions you have about being in a certain place at the time of death. For reasons we cannot understand, family members often slip away when least expected, in the one minute you take to run to the bathroom, or the five minutes when you accidentally doze off. Best to trust that death will happen when it happens, and is ultimately out of our hands.

Expect a wide range of emotions, from sorrow, relief, and confusion to disorientation and numbness. These emotions are expected and normal.

After death has occurred, allow yourself as much time as you need to stay with your family member. There is no hurry.

Care well for yourself. As you leave behind this caregiving phase and enter a new one, give yourself time to rest, reflect and grieve.

- Non-responsive with no voluntary movement
- No food or fluid intake
- Glazed fixed stare
- Breathing changes with longer periods where breathing is absent
- Comatose
- Declining heart rate and blood pressure
- Gurgling sound from the throat (sometimes called the “death rattle”) may be present
- Absence of breathing and pulse
- Arms reaching up and/or head moving forward
- Expression of peace on the face
- Skin is cold
- Change in room temperature or physical sensations may be experienced by family members

## Resources Are Available to Help You Care Well.

Senior LinkAge Line® is a free phone service that connects caregivers and the people they care for to resources including health insurance counseling, respite care, caregiver education and training, support groups, personal and in-home services, home health care, transportation, meals, cleaning and yard work services, home modification and adult day services.

Call the Senior LinkAge Line® at  
1-800-333-2433

[www.MinnesotaHelp.info](http://www.MinnesotaHelp.info)™

Hospice is a specialized form of care for individuals in the last stages of a terminal illness. Hospice care provides physical, emotional and spiritual support for dying individuals and their families. For more information on Hospice call

1-800-214-9597 or visit the Hospice Minnesota website: [www.hospicemn.org](http://www.hospicemn.org)

For information about health care directives, talk with your health care provider or attorney, or call the Senior LinkAge Line®.

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This information is available in other forms to people with disabilities by contacting us at 651-431-2500 or 1-800-882-6262 or through the Minnesota Relay Service at 711 or 1-800-627-3529 (TDD), 1-877-627-3848 (speech-to-speech relay service).

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