

Caring for a Seriously Ill Person at Home: Guidelines for the Caregiver¹

Table of Contents

- A. Introduction
- B. Patient Plan of Care
- C. Caregiver Support
- D. Availability of Supplies
- E. Medications
- F. Physical Comfort Measures
 - a. Physical Pain
 - b. Shortness of Breath
 - c. Nausea
 - d. Anxiety/Restlessness/Agitation
- G. Other Comfort Measures
 - a. Repositioning/Transferring/Lifting of the Patient
 - b. Skin Care
 - c. Mouth Care
 - d. Clothing
- H. Toileting and Hygiene Supplies
- I. Equipment
 - a. Personal Protective Equipment
- J. Laundry and Cleaning
- K. Nutrition
- L. Planning for Death
- M. Patient Decline
 - a. Signs and Symptoms of Approaching Death
 - b. Signs of Death
- N. After Death
 - a. Funeral Planning
 - b. For Caregiver's Peace of Mind

¹ Any Hospice or Palliative Care Program is free to adapt these Guidelines as necessary.

Section A. Introduction to Guidelines for the Caregiver

This document is intended to provide the guidance to care for a family member or friend at home when professional caregivers or inpatient facilities are not accessible. Your having received this document means that there is a public health emergency in your community and healthcare facilities have been overwhelmed.

Taking on the care of someone seriously ill, especially when you may have little or no care-giving experience, can feel overwhelming. It is important to remember that remaining calm and using common sense will make the experience less fearful. Seriously ill and dying persons have been cared for at home by family for centuries...long before hospitals and inpatient centers were developed. Trust your ability to care for a loved one and be guided by your love and by how you would want to be cared for if you were in the same situation.

It is important for you to know that your loved one is dying. As you follow the Patient Plan of Care and the guidelines in this booklet, you must realize that nothing you do or do not do will cause the death of your loved one.

Section B. Patient Plan of Care

The medical provider for your family member or friend may have provided you with a Patient Plan of Care. This Patient Plan of Care will include the following information:

1. Patient Diagnosis and Status
2. Medications
3. Signs and Symptoms to Expect
4. Contact for Assistance
5. Instructions and Resources for Care of Patients

Note: Your medical provider may use a Patient Plan of Care that may be different from the one outlines here, but will include the information you need as a caregiver.

The following topics will help you prepare for your caregiver role.

Section C. Caregiver Support

Due to the public health emergency, support and resources to assist you may be very limited. Your local healthcare organizations in the community have worked together to develop resources to assist you in your role as a caregiver. If resources are available, you will find them listed in the Patient Plan of Care.

In addition to these guidelines to help you care for your family member or friend at home, your healthcare provider may be able to provide you with a telephone number to put you in contact with a person to whom you can ask questions. This person may be able to assist you in finding the help and support you are requesting. This telephone number will be listed in the Patient Plan of Care.

Here are further suggestions to help you find resources in your community:

1. Think about the people you know who are professional caregivers or who have experience with care-giving. Often times, there are family, friends and neighbors who have training or experience in care-giving. Access your personal resources to help support you in your caregiver role.
2. Take inventory of the informal community supports that are available. Consider interfaith church groups and service organizations (such as Rotary, Kiwanis, Lions/Lioness Club) that may have people to assist you, or refer you on to someone who can.
3. In a pandemic, for example, help from typical resources such as hospitals and public health may not be readily available. It is especially important for you to take care of yourself to remain healthy, so you can continue to take care of someone else.

Section D. Availability of Supplies

In a public health emergency it is very likely that supplies necessary may be in short supply. The information in this booklet assumes that supplies such as medications or hygiene products may not be readily available and thus provides you with helpful information on how to be creative and use what usually you have available around the house to help you in providing care.

Section E. Medications

It will be helpful to make a list of all medications that the patient is currently taking, what problem the medication is addressing and in what form the medications are being given. For example, medicines are given by many different routes; by mouth with a pill or liquid, rectally with a suppository or some medicines are administered to the patient through a patch on the skin or a mechanized pump. The Patient Plan of Care attached to this document will help you organize a list of what medicines the patient is taking, how they are to be given to the patient and at what time.)

Pain Medicine: There are two types of pain medicines, non-narcotic and narcotic. Advil (ibuprofen), Tylenol acetaminophen) and Aleve (naproxen sodium) are examples of non-narcotic medications and are generally used for mild pain. There are many types of narcotic medications which are generally prescribed for more severe pain. Morphine is a common narcotic medication prescribed for palliative and

hospice patients. Unfortunately, side effects are common with narcotic medications; side effects include drowsiness, constipation and nausea (see Comfort Measures and Nutrition section of this document for ways to address these side effects).

1. You should not worry that the patient will become addicted to a pain medication or that a medication may in-advertently cause a person's death. Pain medicine is usually prescribed in smaller, tolerable doses and then may be increased to provide maximum comfort.
2. Pain medication is most effective with regular dosing and when it is given on schedule. Do not wait until the patient has complaints of pain before you give the medication.
3. Assessing Pain: Pain management experts recommend believing that the pain is what the patient says it is. It is important to encourage the patient to be honest about what they are feeling and to describe what kind of pain they have. Remember that people have different pain thresholds and the patient's other worries (emotional, psychological and spiritual) may contribute to their perception of physical pain.
4. Use of the Facial Pain Scale on page 14: Using the facial pain scale will help you know if the medicine is helping the patient's pain or if changes need to be made. You can ask the patient to rate their pain on a scale of 0-10, 0 meaning no pain and 10 meaning the worst pain. Or the patient can point to a facial expression on the facial indicator sheet to rate their pain.
5. When a patient is unable to verbally express their pain, there are other ways pain is expressed. Facial grimacing or moaning may indicate the patient is in pain.
6. Assess the patient's pain often by simply asking if they are comfortable. Keeping a record of what time you assessed the patient's pain, the patient's rating of their pain and what medicine was given, will help you keep the patient comfortable.
7. Patients may experience break-through pain, which means that the pain returns before it is time to give the next scheduled dose. It may be wise to have a back-up medicine in the home just in case the patient needs it. However, you should realize that medicines may not be possible to control or alleviate all the pain that a patient may be experiencing. The Patient Plan of Care may include guidance on pain medication and also refer to Section F: Physical Comfort Measures.
8. Other Medications: Patients may be taking other medications for a range of health problems they are experiencing. Keeping a record of symptoms and the patient's reports of discomfort will be helpful information for making medication changes.

9. Again, in a disaster there may not be medication available, but there are things that you can do to help alleviate the patient's pain. (See Physical Comfort Measures later in these guidelines)

Section F. Physical Comfort Measures

There are many measures you can take to help your family member or friend to be as physically comfortable as possible.

Physical Pain: Help the patient focus their attention on something other than their pain. A patient's pain can be lessened by distraction, massage, relaxation exercise, the application of heat or cold near the pained area or a combination of several of these methods.

1. **Distraction:** Read a story, play music, sing or pray with the patient. Ask the patient to tell about some of their favorite memories of travel or of childhood. Look through old photos, scrapbooks or favorite magazines.
2. **Massage:** Use a few drops of lotion, baby, mineral or even vegetable or olive oil, to offer the patient a gentle massage. *Human touch* can be very effective for reassuring the patient and helping them feel secure.
3. **Relaxation Exercises:** Provide simple guided imagery to the patient. Ask them to tell you about a place where they are most comfortable (a warm sandy beach) and in their mind to go there. Expound on this imaginary place, talking slowly and quietly.
4. **Repositioning:** Allow the patient to position themselves in the most comfortable position and then assist by propping pillows to help support their body. If the patient is unable to move on their own, reposition them often to prevent positional pain and potential pressure sores.
5. **Application of Hot/Cold to Pained Area:** First, cover the skin with a cloth such as a towel and if available, use an electric heating pad or ice/freezer packs on the pained area. If a heating pad is not available, fill a tube sock with rice or small dried beans and heat slowly in an oven or with a non-flammable heat source. Use frozen bags of vegetables for cold packs and place on the patient's affected area.

Shortness of Breath: Often times, patients get anxious about not being able to catch their breath. Remain calm and provide reassurance to help the patient stay calm.

1. Use an electric fan or create moving air that circulates indirectly on the patient's face.
2. Open a window to allow the outside breeze to circulate room air.

3. Assist patient in finding a position that gives them the most freedom for breathing. Some patients find it easier to breathe sitting up. Encourage the patient to sit up by elevating the head and shoulders with pillows or have the patient sit in a recliner.
4. Encourage “*purse-lip*” breathing (like when you blow out a candle) to help patient breath in and out more slowly and more deeply. ; breathe in slowly through their nose and breathe out through their mouth.
5. If the patient is prescribed morphine, this medication may help stabilize a patient’s breathing. There are also some over-the-counter medications that can help with breathing problems. Benadryl may be helpful, but may cause confusion and sleepiness.

Nausea: Nausea and vomiting are common symptoms associated with (some) disease and can also be a side effect of a medication. Medicines can be ordered by a physician that can help with these symptoms. The following are things you can do:

1. Offer the patient fluid as tolerated and prepare bland, smaller portions of soft and cool foods such as broth, rice, apple sauce or dry toast.
2. Ask the patient what tastes best and respect their choices if they cannot eat anything at the time.
3. The flavor of ginger naturally settles an up-set stomach and helps nausea. Offer ginger-ale soda, ginger tea or a small amount of fresh ginger infused in water.
4. Carbonated water or soda or soda crackers can also help settle an upset stomach.
5. Avoid preparing the patient greasy or spicy foods and avoid strong cooking odors.

Anxiety/Restlessness/Agitation: Anxiety is one of the most common symptoms associated with illness. There are multiple reasons why a patient may feel anxious, restless or agitated. They may be experiencing bodily changes, physical pain or discomfort or unresolved emotional or spiritual issues. There are medications that can help with these symptoms. The following are things you can do:

1. Remain calm and reassure the patient of your presence. Reassure in a slow, calm manner.
2. Reassure the patient that he/she is not alone.
3. Use distraction or redirect the patient as a means to take their mind off how they feel.
4. If the patient is alert, gently explore how the patient feels to identify the cause of their symptoms.

5. Refer to other tips noted in Physical Comfort Measure section of these guidelines.

Section G: Other Comfort Measures

When people are unable to physically exercise or move about on their own, they may need assistance from a caregiver for activities of daily living, such as bathing, toileting, dressing and perhaps eating. If the patient is bed-bound, they may also need assistance to move and turn while lying down in bed.

Repositioning/Transferring/Lifting of the Patient:

1. *Make certain you are physically capable of handling the weight of the patient if they can only partially assist in transferring.* **If you cannot safely transfer the patient leave the patient where they are. You do not want to hurt the patient! And you will not be able to help the patient if you hurt yourself.**
2. If it looks like a patient may fall during a transfer, gently lower them to the floor/ground. Make them comfortable with a pillow or any available padding, and cover them with a blanket before you seek help.
3. Use a sturdy belt or a heavy piece of material cut in a long strip to place around the patient's waist or grab the waistband of the patient's pants to assist them in making a transfer. Note the position of your body and feet when you help lift the patient so you do not become unbalanced.
4. You can reposition or lift a bed-bound patient with the use of a draw sheet or blanket. Quarter a regular size flat sheet (width-wise) and position from under patient's shoulder to under the buttocks (to support spine). The caregiver(s) can then pull the sheet to reposition the patient from side to side and/or tuck pillows in to help support the patient lying on their side. Encourage the patient to position themselves in the most comforting position.
5. If a patient is bed-bound, it is important to reposition them frequently, every 2 hours, to avoid skin breakdown. Bed sores (or pressure sores) are caused from lying in one position too long.
6. Keep bottom sheets pulled tightly and smooth to reduce the chance of skin breakdown. You can sprinkle the bottom sheet with a bit of cornstarch or talcum powder to reduce potential skin friction.

Skin Care:

1. Keeping the patient clean and dry is important to promote comfort and prevent skin breakdown. If you have ample water, a simple (bed) bath can be performed

with a small basin of warmed water and a small amount of soap. Place a towel under the area that is being cleansed; wash, and towel dry well.

2. If a patient is bed-bound and incontinent (no control of bowels and bladder), it is important to keep this area clean and dry. Wipe area clean and rinse with water or anti-bacterial wipes such as baby wipes or disposable cleaning cloths. Vaseline, zinc oxide, baby diaper ointments or other skin protecting ointment can be lightly applied to prevent a rash or chafing.
3. For dry skin, a few drops of baby, vegetable or olive oil can be added to the basin of water, or gently massage in a non-sticky lotion.
4. Protect skin contact areas such as knees or ankles from bedsores by placing soft pillows or a rolled up towel or blanket under each area. A rolled up washcloth, taped into a “donut shape” will prevent ear sores when a patient is lying on their side.
5. If skin becomes reddened due to the patient lying in one position too long, assist the patient in repositioning of the reddened area. If pressure sores open, wash with soap and water and keep dry.
6. Itching can accompany some medications and illnesses. Sooth itchy skin by keeping it clean and dry. Use mild soap and water and mildly medicated lotions. Keep patient’s fingernails short and smooth to avoid damaging their skin.

Mouth Care:

1. If available, use a sponge stick to swab out patient’s mouth.
2. Wrap a thin, clean soft washcloth on your finger to swab out the patient’s mouth and to clean the tongue.
3. Wrap gauze or cheese cloth onto a Popsicle or clean wooden stick, wet in water, and gently swab out the patient’s mouth.

Clothing:

1. Cut cotton t-shirts or pajama tops down the back and sew on ties for ease in dressing, bathing and increased dignity for the bed-bound patient.
2. Use satin type clothing for gowns or pajamas for ease in moving a patient in bed. For persons who are prone to sweating, use 100% cotton or cotton blend clothing that absorb moisture and breathe well.

Section H: Toileting and Hygiene Supplies

If a patient is unable to make it to the toilet, there are other options for caring for elimination. There are many common household materials that will work for absorbent bed pads and adult hygiene supplies when these items are not available.

1. Clean private area with soap and water after each urination and stool. Keep patient clean and dry.
2. Protect yourself by washing your hands thoroughly after tending to patient. If available, use dish-washing or water-proof gloves to protect you.
3. If the patient cannot safely get out of bed to use the toilet, then use some of the following methods so that the patient can go to the toilet in the bed.
4. If adult hygiene pads (such as Depends) are not available, you can make an adult diaper by cutting sheets, towels or old cotton material (tablecloths) to the body sizes that are needed. Leave enough material on one side to tie together, or affix sticky Velcro straps or safety pin to make a closure on one side. Large plastic bags can be cut as a protective over layer.
5. Female sanitary pads can be used for absorbency for toileting needs.
6. IF absorbent bed pads are not available, place a clean plastic garbage bag under an absorbent flannel sheet or blanket to keep the bed linens and mattress from being soiled. Flannel sided vinyl tablecloths and soft rugs with rubber backs also work well.
7. If it is unsafe to move the patient for toileting, use a bed pan or allow the patient to toilet directly into absorbent bed pads. Clean the patient and replace with clean bed pads thoroughly after each toileting.

Section I: Equipment

Medical equipment such as hospital beds, walkers, commodes, toilet seat risers, safety rails and bathroom handles provide both comfort and safety to patients. There may be community loan closets that have used equipment (see your local Salvation Army or American Red Cross). In the event this equipment is not available, many of these items can be constructed by improvising with common household furnishings and materials. Some examples include:

1. Beds can be easily elevated by placing cement blocks (flat) under the four bed legs and several under the bed to support the frame. A higher bed will make it easier to care for a bed-bound patient. Make certain the bed is supported properly for weight distribution.

2. Ropes or knotted sheets can be affixed to the end of a bed with length long enough for the patient to pull themselves upright, or reposition in bed.
3. A commode can be made out of an old wooden chair. A hole can be made in the middle of the seat to hang a bucket inside or place it on the floor under the chair.
4. A cane or walker can be constructed out of lightweight wood pieces, screwed together. Short smooth wood pieces or old pipes can be affixed to walls for bathroom safety rails.
5. Plastic lawn chairs make good shower chairs.
6. Rolling desk chairs can be used in place of a wheelchair to help the patient get around their home more easily.
7. If a patient is not able to walk stairs, they may be able to sit on the step backwards, and left themselves up each step until they reach the top.
8. A lightweight chair can be used as a walker.
9. Re-arrange furniture to make home navigation easier so that the patient can use furniture as a support as he/she walks around. Avoid the use of throw rugs to prevent falls.

Personal Protective Equipment such as latex gloves, protective eyewear and biohazard boxes for needles help protect the caregiver and patient from infection. In the event these items are not available, you can substitute with other items found in the home.

1. Use a clean pair of dish-washing or water-proof gloves. A thin (softer) plastic bag that forms over the hand or fingers will also work.
2. Safety glasses or any clear plastic or non prescription glass framed glasses will protect eyes from splashes of body fluids.
3. An empty plastic laundry detergent bottle works well for disposing of used needles. Seal the bottle when it is $\frac{3}{4}$ full and place in a secure place or dispose of according to public health authority directives.
4. If there is the potential for the splattering of any body fluids, use a garbage bag as an apron when you are working with the patient.
5. All family members should wash their hands with soap and water frequently and use other hand cleaning materials such as hand gels to reduce chance of infection. **Hand-washing is the most important thing you and other family members can do to prevent the spread of infection.**

Section J: Laundry and Cleaning

Maintaining sanitary conditions to keep bacteria from collecting is important for both the patient and caregiver's health.

1. If water is ample, launder clothing and bed linens frequently with detergent. If water is not available, use paper products for cleaning and for immediate disposal. Dispose of refuse in garbage bags, and place out-of-doors in a secure receptacle.
2. For infection control, wipe down frequently daily with a small amount of bleach to clean horizontal surfaces and any other areas touched by caregivers or the patient such as door knobs, light switches. Clean up spills with a mixture of 1 Tablespoon of regular bleach to 1 gallon of water.

During an actual emergency, public health authorities will also provide information about infection control through the media.

Section K: Nutrition

Seriously ill persons generally have a decreased appetite or no appetite at all. They are using less energy and the lack of appetite is a natural part of disease progression. It is important not to force foods on the patient. Offer small portions of anything that the patient feels will taste good and allow the patient to be in control of their food and water intake.

When a person is nearing death, it is natural that they stop eating and drinking altogether. Their body is slowly shutting down normal body functions...this is nature's way of helping the person die in a more comfortable way. It is also OK for the patient to cease taking in fluids; dehydration is not painful and is a normal process as the body prepares for death. Death is not caused by starvation.

1. Offer choices of the patient's favorite food and drink, but do not force any foods or fluids on the patient. Allow the patient to be in control.
2. Accept the loss of appetite as an expected and normal part of disease progression.
3. Constipation is a common side effect of medication, especially narcotics. Stool softeners and mild laxatives are often prescribed with medications. Avoid binding-type foods such as chocolate, cheese and other milk products.
4. If the patient is still taking nutrition, a recipe can be mixed of applesauce, prune juice and bran to help with constipation.
5. It may be normal for a patient who has ceased taking in food not to have a bowel movement.

6. When a patient is nearing death, additional fluids may actually make the patient more uncomfortable as urine output slows and fluids collect in the lungs and throat.
7. To moisten the patient's mouth, use small ice chips, popsicles or swabs dipped in water with a few drops of vegetable oil. (Swabs can be made by attaching gauze, cheesecloth or any piece of clean soft cotton material, rubber-banded to a stick). If a patient is not at risk of choking, sucking on hard candy (lemon drops) can help stimulate saliva flow.

Section L: Planning for Death

While your family member or friend is still alert, ask them if they have thought about what they want for their funeral and burial. By involving the person in planning, it will make it easier for you to carry out their wishes. You can engage them in discussion by asking the questions such as the following to help them make plans:

- Do you want burial or cremation? What cemetery? Mausoleum? Funeral Home?
- Do you want a funeral ceremony? In church or in other setting? Music? Requests for Eulogy?
- Do you have special monies set aside to pay for services?

You should accept the fact that some may not want to talk about death and/or family members may be hesitant to discuss this with the family member who is dying.

Special Directives:

Depending on the type of disaster, there may be special directives or announcements about burials put out by Public Health. Funeral directors will be able to instruct you about special any special arrangements that may be required by public health authorities.

Section M: Patient Decline of Mind, Body, and Spirit

As a person's physical health declines, it is normal that they begin to withdraw and to take less and less interest in the outside world. They begin to sleep more or rest with their eyes closed. This is due to having decreased energy but also the need to privately process...within their own mind, all the changes they are experiencing. Try to understand that withdrawing is normal for a dying person and should not to be taken personally by loved ones. It is important not to try to "cheer up" the patient but allow the person to process what is happening to them in their own way. People continue to process the changes brought on by each step of decline.

As a person goes about reconciling their dying, try to be aware of their emotional, social, psychological and spiritual needs. Often, people will do a life review to assign meaning to their life experiences and bring closure to the people and relationships

they have had. People may or may not need, or want, to talk about death. It is important to be available if they want to verbally process their feelings, but avoid prying with questions about their feelings. Be available to listen and take your cues from how much the person needs to express their thoughts and feelings. Sometimes holding a hand in silence speaks louder than words.

As disease progresses, physical functions also change and slow. The person will have less and less need for food and drink. They may become too weak to walk or move about on their own. They may experience bouts with, or be totally incontinent (loss of control) of bowel and bladder function. As a result of lower blood pressure and changes in body temperature, the person's skin may be pale and feel clammy. Breathing patterns may be inconsistent, fluctuating between shallow breaths, periods of accelerated breathing or long periods of no breath. Sometimes fluids collect in the lungs, esophagus or back of throat and a "gurgle" sound is made as the person breathes. Often a person is too weak to cough up this excess fluid. This is normal. The patient is not in distress.

Although there is no way to anticipate how rapid a person will decline or when death will happen, there are changes that indicate when a patient has entered another level of decline. A dying person will begin to sleep almost full time. They can be awakened from sleep but may be disoriented off and on, and confused about people and places. They may "pick" at the air or at their clothing. They may talk about things that they see but you cannot, or reach out to people who have died. They may speak about their impending death in terms of preparing for a journey, standing in line or getting everything in order. Listen and gently help them explore their experience. Gently reassure the patient if they seem frightened by the visions. These *special communications* are helping them transition between life and death and preparing themselves for "letting go."

Signs and Symptoms of Approaching Death

1. The dying person may become more restless or be un-responsive to stimulation. The eyes may be semi-open without seeing, and have a glazed appearance. If the dying person seems restless, you may comfort the patient by holding his/her hand, touching or gently stroking him/her and speaking in soft tones to reassure him/her of your presence.
2. The hands and feet may become cool to touch, and may take on a purplish or red-blue blotchy color, especially on the undersides of the arms and legs. This is due to a slowed circulation. Use lightweight, warm blankets to keep your loved one comfortable. Some patients may not like to be covered up.
3. Breathing patterns becomes irregular and may stop for seconds to minutes, and then begin again. This is also due to decreased circulation. Elevating the patient's head may help their breathing.

4. Secretions may become thicker and impossible for the patient to cough up. If available, a cool mist humidifier may be helpful. Position the person on his/her side and elevate their head with extra pillows.
5. Bowel and bladder control may become weak or absent. Use pads under the buttocks and clean the genital area often to keep the patient dry and comfortable.
6. Foods and fluids may no longer be taken in. Moisten the mouth with a sponge swab or a soft wet washcloth. Moisten lips with lip balm, Vaseline or small amount of vegetable oil.
7. Senses will lessen as the nervous system functions slow, but the sense of hearing remains until death. Continue to talk to the person and assume that they can hear what you are saying. Keep diffused lighting on in the room as it may help keep the person oriented and calm.
8. A day or hours before death, it is not uncommon for a dying person to suddenly become alert, sit up and visit with family, or eat food when they haven't eaten for many days. This surge of energy is thought to be part of the transition between life and death. This does not mean that the patient is recovering.
9. Saying your heartfelt goodbye to your family member or friend will give them permission to die. Often family members will hang on for their loved ones. Telling them it is OK to let-go will help them release from this world.

Signs of Death:

- No breathing
- No heartbeat
- No response to shaking
- Eyes fixed, eyelids slightly open
- Jaw relaxed and mouth slightly open

Section N: After Death

Funeral Planning: You as the caregiver or another family member should contact the Funeral Director for burial arrangements. If the community is experiencing a large number of deaths due to the public health emergency, there may be certain directives about burial that must be followed. The Funeral Director will help you through this process.

1. If possible, it is helpful to contact the funeral home prior to death to inform them of the person's status. This will give you peace of mind and not be rushed when the death occurs. Family and friends can take private time with the deceased and contact the funeral director when they are ready.

2. If you are receiving assistance in the home from hospice, home health or any other medical personnel, contact them when the death has occurred.
3. **Do not call 911.**
4. Follow any special public health directives for infection control. Otherwise follow normal cleaning procedures (Section after the body has been removed from the home).

For the Caregiver's Peace of Mind: It is normal to reflect on your experiences after your caregiver role ends, especially because so many emotions come over you when you are under stress. Undoubtedly you will have many feelings about what did, or did not happen. It is best to focus on the positive and to realize that you did the best you could do. Find someone who is a good listener and can understand your feelings so you can talk through your thoughts and feelings about your care giving experience.

These Guidelines, **Caring for a Seriously Ill Person at Home: Guidelines for the Caregiver** are made available to you from (name of your organization) and the following topic experts:

Teresa Anderson, RN, BSN, Manager, St. Clare Hospice House, Home Health United, Baraboo, WI

Lisa Becker, Palliative Care Coordinator, Eagle River Memorial Hospital, Eagle River, WI

Sarah A. Becker, MSSW LCSW, Manager, Social Services/Continuing Care, Aurora St. Luke's Medical Center, Milwaukee, WI

Linda Bodien, Vice President of Clinical Services, Ministry Home Care, Inc. Marshfield, WI

Lisa DeSieno, MSE, LPC, Director of Outreach, Unity, DePere, WI

Karen Dumke, RN, Case Manager, CHN Home Care, Berlin, WI

Beth Esser RN C, Infection Control/Performance Improvement Manager, Indianhead Medical Center, Shell Lake, WI

Melissa Hirsbrunner, MS, RD, CD, Clinical Dietitian, Froedtert Hospital, Milwaukee, WI

Anne LeMere RN, BSN, CHPN, Director of Compliance, Unity, DePere, WI

Karin Meier MS RN CHPN, Palliative Care Manager, Saint Joseph's Hospital, Marshfield, WI

Melanie Ramey, Executive Director,

Mark Repenshek, Ph.D., Health Care Ethicist, Columbia St. Mary's Health System,
Glendale, WI

Peggy Ruedinger, Palliative Care Coordinator, Mercy Medical Center, Oshkosh,
WI

Dennis Tomczyk, Director, Hospital Preparedness, Wisconsin Division of Public
Health, Madison, WI

Susan Wurzer, The Hope of Wisconsin, Madison, WI

Patti Zaremba, RN, Case Manager, Palliative Care Coordinator, Howard Young
Medical Center, Woodruff, WI

Colette Zunk, CSW, Palliative Care Coordinator, Sacred Heart-Saint Mary's
Hospitals, Inc., Rhineland, WI