RELIANCE HOSPICE

Patient Handbook

(760) 423-6924

RELIANCE HOSPICE HANDBOOK

Introduction

Our mission is to provide quality services, with compassion, to the patient and their family during the end of life's journey.

Reliance Hospice seeks to provide care and support to both the patient and the family.
The primary goal of Hospice is to help people live as fully as possible, in their own surroundings, and in the company of beloved family and friends.

This guide is designed to serve as a reference to assist the patient and caregiver(s) to become familiar with the Hospice program and services that we provide.

You will read in this book that hospice operates as an interdisciplinary team. No one person has the expertise to meet all of your needs. The Interdisciplinary team consists of the patient and family, doctors, nurses, home health aides, social workers, spiritual care counselors, volunteers, dietary and other therapists and bereavement personnel. *The most important members of that team are the patient and family.* We are here to *assist* you and to *work with* you throughout the course of your illness so that you can maintain dignity and achieve comfort and peace.

Hospice is a unique service provided by specialized professionals. The interdisciplinary team carries out an individualized plan of care to address a person's medical, emotional, psychosocial and spiritual needs. Furthermore, we recognize that you do not go through your illness alone. The plan also extends to your family members and friends. Please note that our comprehensive and responsive services are available 7 days a week, 365 days a year.

You may have many questions about the hospice program and services and we encourage you to ask your nurse, social worker, spiritual counselor, certified hospice aide, or any member of our staff to respond to your questions or concerns.

We want the information provided in this booklet to be useful and helpful. Please share any ideas or thoughts you have to improve it with any member of the Reliance Hospice team.

If at any time you have any questions, comments or concerns regarding the care being provided, please do not hesitate to call us at **(866) 569-7922 or (760) 423-6924.**

Thank you for allowing us to take this journey with you. It is our privilege to serve you and your family.

The Reliance Hospice Team

GENERAL HOSPICE INFORMATION

LEVELS OF CARE

Routine Care

Hospice believes in caring for patients in whatever setting you call home. Care may be provided in a skilled nursing facility, assisted living facility, board & care, or in the patient's own home. We strive to ensure that medical, social, spiritual and emotional needs of our patients and families are met.

Routine care involves intermittent visits by interdisciplinary team members (nurse, social worker, hospice aide, spiritual counselor, hospice medical director, volunteers, etc.) as determined in your plan of care. In addition, all medications, durable medical equipment and supplies related to your illness will be provided. An emphasis is put on the management of symptoms and the education of the patient, family and caregiver relating to the physical, emotional and spiritual changes that may occur and how you can best manage those changes.

General Inpatient Care (provided in contracted care facilities only)

General Inpatient Care is provided when a patient requires increased skilled nursing care for management of an acute medical crisis (pain control and/ or symptom management) that cannot be controlled in the home setting. The patient will be transferred to a contracted skilled nursing facility for a short-term stay until pain or symptoms are under control. Once symptoms are managed the patient will return to the home setting.

Respite care (provided in contracted care facilities only)

Respite care is short-term inpatient care in a contracted skilled nursing facility when it is necessary to relieve the family members or other persons caring for the patient and provide them a short rest period. If qualified, Respite care may be provided for up to five consecutive days.

Continuous Care

Continuous care is provided in the patient's home during a period when physical or emotional symptoms are not able to be controlled under routine care. The patient must require primary nursing care for palliation or management of actual physical or emotional symptoms to be eligible to receive continuous care. Continuous Care is considered a short-term level of care and is re-evaluated every 24 hours.

THE TEAM APPROACH TO CARE!

No ***one*** person can provide for all the needs of Hospice patients and their caregivers. Therefore, Reliance Hospice provides care by a ***team*** of people, with different expertise, working together. This team consists of the following people:

1. *Patient, Family, and Caregiver(s)*. Reliance Hospice is committed to maintaining the integrity of the patient's right to self-determination. This means that we need your active participation, to the best of your ability, in the planning and implementation of your care. You can provide the team with vital information about your needs and the methods of care which are best able to meet those needs.

2. *Attending Physician*: The patient's primary physician, also known as the attending physician, is a key member of the hospice team. The attending physician assumes responsibility for medical management of the patient's treatment throughout involvement in the Hospice program. You have the right to change your attending physician at any time.

3. *Hospice Medical Director*: The Reliance Hospice Medical Director is a physician with special education, interest and expertise in the care of patients with life-limiting illness. He/she is considered an employee of Reliance Hospice and is available to serve as the attending physician for any patient who receives care from Reliance Hospice. Whether or not a patient elects to have the Medical Director become their attending physician is their choice.

4. *Nursing Staff*: Hospice nurses visit the patient in their home, nursing home, board and care, assisted living or anywhere that the patient calls home. The visit schedule depends on the patient and family/caregiver needs. The nurses provide expertise in assessing and managing symptoms. The nurse also serves as the eyes and ears for the physician and keeps the attending physician informed about the patient's condition. The nurse also provides education to the patient and family regarding disease process and the care needs of the patient.

5. *Social Workers:* Hospice social workers are available to assist the patient, family/caregiver in many ways. No need is too small to address with the social worker. Often just talking with the social worker brings comfort. With any life-limiting illness it is normal to experience a wide-range of emotions, including things such as grief, anger, resentment, frustration, even depression. An important part of the social worker's role is to assist with expressing and understanding the challenges of this stressful time. They also can provide referrals to other community resources that are available to help to improve your quality of life.

6. *Spiritual Counselors:* Spiritual care is offered to each patient and family/caregiver who desires visits by our full time Spiritual Counselors. It is not our goal to replace the patient's church family, if one exists, which has provided them support throughout their life, but rather to work with the patient's clergy to supplement the spiritual care provided when this is the patient's desire. Our spiritual counselors are non-denominational and have no agenda. The spiritual counselors provide only an open heart to allow the patient's agenda to direct the

course of spiritual care. Our full time spiritual counselor has expertise in spiritual care at the end of life, as well as work in grief counseling. The spiritual counselor is also available to provide funeral/memorial services.

7. *Certified Hospice Aides:* The CHA is available to assist patients with their activities of daily living, and to provide total care for those patients who need it. The frequency of visits is based on the patient's needs and the care plan as ordered by the RN. Our nurse will perform supervisory visits on an ongoing basis to assure your needs are being met.

8. *Homemaker services:* The CHA is also available to provide support to the patient and their family by providing light housekeeping in immediate patient area and light meal preparation.

9. *Volunteers:* Reliance Hospice has trained volunteers who provide a break to patients and caregivers through such things as:

    - Sitting with the patient (reading, writing letters, listening to music or simply providing presence)
    - Running errands to help the patient/caregiver
    - Assisting in any way which is helpful and mutually agreeable and safe for the patient
    - Volunteers may not provide any physical care to the patient

    You only need to ask for volunteer services to be connected with a Reliance Hospice volunteer.

UNDERSTANDING THE CARE NEEDS OF THE HOSPICE PATIENT

COMMON SYMPTOMS

ACTIVITY AND REST

Most patients like to be active and involved with family life as long as they can. If strength permits, patients may dress for the day, join the family for meals and other activities, and go for short outings. When someone is ill and strength is limited, activities should be moderate. Conserving energy is more productive than trying to do too much. To conserve the patient's energy, alternate activities with rest and utilize durable medical equipment such as a wheelchair, bedside commode, or shower chair to help the patient maintain independence and safety while still conserving energy.

An electric hospital bed is helpful when the patient is too ill to get out of bed or experiences difficulty in finding a comfortable position in a traditional bed. It allows the patient to change his/her position with the controls and lets the caregiver adjust the height of the bed when giving care. The bedrails assist with safety and can help the patient turn him/herself in bed by giving him/her something to hold onto when moving from side to side. In addition, the head of the bed can be raised to help with breathing and for meals. The hospice nurse will assist you in determining what equipment will be most helpful and how to obtain it.

ANXIETY/CONFUSION

Many patients may experience anxiety or confusion during the course of their illness. Changes in metabolism and disease processes affecting the brain or liver are some of the physiological reasons this may occur. When a person becomes confused, he or she may be aware of the confusion and become anxious about this loss of control. The following suggestions may be helpful in caring for a patient who is anxious or confused:

- Be aware of safety issues. Confused patients may try to get out of bed when it is not safe to do so.

- Have a clock and calendar within sight to help keep the patient oriented.

- Remember, changing routines or environment may cause confusion. Keep the patient in a quiet, well-lit, familiar room with familiar people.

- Do not treat the patient as if he or she doesn't know what is happening.

- Remain calm and reassuring to the patient. A caregiver's anxiety will only increase a patient's anxiety.

- Helping the patient to remain calm and relaxed counteracts the effects of anxiety.

- Certain medications can help clear confusion and reduce anxiety. Ask the Hospice nurse about those medications.

NOTE: If anxiety and confusion problems continue, call the Hospice office for further professional guidance.

BATHING

A bath or shower is always refreshing. However, there are times when a bath or shower is not convenient or possible. In such instances, bed bathing may be a desirable alternative for the patient. Hospice has Certified Hospice Aides who can assist caregivers in bathing patients. Please consult with the Hospice Nurse to arrange for a CHA, if needed.

If the caregiver chooses to bathe the patient in bed, she/he may find the following suggestions helpful:

- Gather all the necessary items for the bath, and place them near the patient.
- Be certain the water being used is warm.
- Change the water frequently, if necessary, to maintain freshness and temperature.
- Be certain the patient remains warm throughout the entire process. This might entail covering the parts of the patient's body which are not being washed with a sheet or light blanket.
- Use soap sparingly and only on those areas of the body which perspire or are in need of extra cleansing due to odor or drainage. Use latex gloves if there is body drainage.
- Soaps can cause dryness and irritation. Plain, warm water is usually sufficient. If the skin is dry, a capful of baby oil or baby lotion in the water can be helpful. Should the skin remain dry, the use of skin moisturizers may be helpful.

An alternative to a bed bath is a bath while sitting on a chair or commode either next to the sink or, if the patient is able, while sitting in the shower. (NOTE: If the patient is receiving radiation, do not use any soaps or lotions on the radiated area.)

BREATHING PROBLEMS

For a patient who is very ill, the process of getting air in and out of the lungs can be difficult at times. Breathing difficulties are often referred to as “shortness of breath” or “air hunger.” Being short of breath can be very frightening to a patient. It is important that the caregiver try to remain calm and not contribute his or her own anxiety to that of the patient. A soothing presence may restore calmness. Signs of low oxygen may include a restless or anxious feeling, as well as a faster breathing rate. If breathing problems do occur, the caregiver can do some things to help the patient breathe easier:

- Remain calm and reassuring.
- Raise the patient's head by raising the head of the bed or by placing pillows behind the patient's back, neck, and head.
- Place the patient in a position he or she identifies as most comfortable.
- Utilize fans, humidifiers, or cool mist vaporizers.
- Eliminate smoking from the patient's immediate area.
- Place a cool cloth across the patient's jaw/throat area.
- Give breathing medications to the patient, as ordered by the physician.
- Give pain medications or sedation as ordered by the physician. (Remember that pain can increase the feeling of being short of breath.)

Call Reliance Hospice at **(866) 569-7922** if the above measures are not improving the patient's symptoms.

CONSTIPATION

Keep a log or calendar that notes when the patient has a bowel movement. Do not expect a bowel movement daily if the patient is eating poorly, but do expect one about every three days. Notify the nurse early in the day if you think the patient is having a problem with constipation so s/he can plan a visit. Give ordered laxatives on a regular basis. Remember that pain medications can be very constipating. If the patient is receiving pain medication, laxatives are usually needed. Increase the patient's fluid intake if possible.

EMOTIONAL HEALTH

When caring for someone with a life-limiting illness, emotional symptoms must be monitored and addressed along with physical symptoms. Patients and their loved ones experience numerous changes – emotionally and physically – as the disease progresses. It is important for caregivers to recognize and understand these changes and for caregivers to receive support. Changes vary from person to person depending on the individual's perspective, support systems, longevity of the illness, and prior coping mechanisms.

Everyone handles stress differently, and there is no right or wrong way to react to a stressful situation. It is important to recognize when stress becomes unmanageable and to be able to take corrective action. Some signs of stress are:

- Depression
- Confusion and difficulty concentrating
- Mood changes
- Frequent crying spells
- Changes in sleep and appetite patterns
- Increase in cigarette, alcohol or drug use
- Irritation
- Laughing and/or smiling less frequently
- Feelings of inadequacy and self-doubt
- Lack of energy
- Muscle tension
- Headache

Experiencing these symptoms may be a natural reaction to coping with a life-limiting illness. However, it is important to be aware of these signs and to seek professional guidance if these symptoms persist. Your hospice care professional may be able to help to improve your coping ability. His or her role includes the following:

Explaining your illness to you and helping you to identify how your illness is interfering with your ability to do things you are used to doing and identify strategies to help

Assessing if your medication is effective

Instructing you on the name, dose, route, purpose, schedule, side effects and storage requirements of your medication and answering questions such as what would happen if you skipped a dose

Setting up a weekly pillbox to help you to remember when, or if, you have taken your medication

Instructing you or your family about any treatments, such as dressing changes

Helping you to communicate your needs and feelings to family members and other healthcare professionals

Helping you to identify past coping mechanisms that have been helpful

Suggesting adaptive equipment that may help you be more independent

Teaching you a number of stress management techniques such as breathing exercises, relaxation techniques, or meditation

Assessing community resource needs within your family unit and making referrals to connect you with resources such as in-home support services, transportation services, legal services, income assistance, home-delivered meals, or help with drug and alcohol problems.

Caregiver Strategies

- **Be good to yourself**. Go shopping, go golfing, go to the hairdresser, take a walk. Do whatever is relaxing and provides a break from the daily routine, if only for a short time. Hospice volunteers are available to sit with the patient if needed.

- **Maintain a proper diet**. The body uses food faster when it is under stress, so a balanced diet is essential. Regular amounts of protein, vitamins and minerals are needed to repair damage caused by stress.

- **Learn to relax**. Find a quiet place to be alone and spend at least 15 minutes there every day to relieve daily tension. Taking a bath, getting a massage or reading are relaxing for some, but everyone should find something that works for them. A “quiet break” also helps to lessen fatigue and refreshes the mind, body and spirit.

- **Learn stress-reducing behavior**. Get into the habit of thinking “could” and “want to” instead of “should.” This helps eliminate self-imposed pressure if the task is not completed or if the desired results are not achieved.

- **Exercise**. This is a great way to relieve physical and mental tension. Exercise brings measurable relaxation as the tranquilizing chemicals called endorphins are released to the brain. It is a natural way to calm the body.

Keep in mind that Reliance Healthcare Social Workers and Spiritual Counselors are knowledgeable about death and dying issues. They are available to help patients, caregivers and family members cope with many day-to-day tasks that often become overwhelming.

The caregiver’s ability to meet the needs of the patient is dependent on his/her ability to care for himself/herself.

It is important for patients to explore their emotional needs and to fulfill them as much as possible. The Reliance Hospice philosophy is that life should be lived to its fullest and that all patients should be kept as symptom-free and comfortable as possible. Patients are encouraged to remain in control of their lives and are urged to enjoy life and to focus on quality time by doing activities they enjoy, such as reconnecting with loved ones, learning a new skill, or doing something they always wanted to do.

FEVER

Fevers are often common in very ill patients. The goal is to keep the patient comfortable. It is not necessary to take a temperature reading routinely. Suggestions to help provide comfort to the patient include:

- Offer extra fluids if the patient is alert and able to take them
- Sponge with lukewarm water
- Cover loosely with a sheet or light blanket

INCONTINENCE (INABILITY TO CONTROL BLADDER/BOWELS)

Occasionally a patient becomes incontinent. As this is a very private time in the care of a patient, it is a good idea to have necessary items on hand that will aide in caring for the patient’s special needs. Disposable undergarments and under pads can be used. The nurse or CHA can instruct in the use of these items. It is important to keep the patient clean and dry in order to prevent or minimize skin irritation and breakdown. Further discussion follows in the section titled “Skin Care & Lifting and Turning Patients.”

MOUTH CARE AND ORAL THRUSH

Mouth care is important when little food or drink is being taken in. The normal release of saliva, which is the body’s own way of cleansing the mouth, does not occur when a person is not eating. In addition, the patient may experience a dry mouth due to:

- Breathing through the mouth
- Increased or continuous use of oxygen
- Certain medications

Regular mouth care helps prevent sores and may improve the patient’s appetite. If the patient is unable to do his/her own mouth care, it will be necessary to do it for him/her.

(NOTE: When providing mouth care, make sure the head of the bed is elevated or the patient is in a sitting position.)

One or more of the following may be used to ensure proper mouth care:

- Soft bristle toothbrush
- Piece of gauze moistened with water
- Soft wash cloth moistened with water
- Toothettes – little sponges on a stick that can be moistened with water or a non-drying mouthwash
- The teeth, gums and tongue should be gently swabbed using any of the above. This can be done several times a day

Further suggestions for maintaining a clean, moist mouth include:

- Moisten lips with Chapstick, Vaseline, or other moisturizer

- Avoid the use of mouthwashes with alcohol, as they can be drying
- Dry mouth can be relieved by sucking on ice chips or hard candies or by frequent sips of water.(NOTE: If there is any difficulty with mouth care, call the Hospice office for further professional guidance)

Oral thrush is a very common infection that occurs in many patients who are very ill. It is an infection of the mouth, tongue and throat caused by microscopic organisms known as yeast. The type of yeast that most commonly causes oral thrush is called Candida and is normally found in the mouth, skin and stomach of just about everyone. The main symptom of oral thrush is the appearance of soft, white patches in the mouth or back of the throat.

Oral thrush is not contagious. When you are healthy and your immune system is strong, it poses no threat. In patients with cancer, the use of chemotherapy and steroids increase the chance of getting thrush. These therapies allow the yeast to grow while suppressing the ability of the immune system to do anything about it.

Because your immune system is already weakened it is very important for you to carefully follow your doctor's instructions. Doctors treat thrush with drugs known as antifungals that help control the infecting yeast. These are prescribed in a tablet or liquid form. If left untreated, thrush may be a bigger problem for you by becoming more severe and painful.

You can do several things to help reduce the risk of developing oral thrush:

- After eating, gently brush all surfaces of your teeth, gums and tongue with a soft toothbrush.
- Gently floss your teeth daily with dental floss.
- Rinse your mouth before and after meals, and at bedtime, with plain water or a mouthwash made from one teaspoon of salt dissolved in one quart of water. NOTE: Avoid the use of commercial mouthwashes.

If you wear dentures, remove and brush them thoroughly after meals and brush your gums and tongue. Your dentures should also be soaked regularly in a cleaning solution.

NUTRITION

Changes in the ability to eat are a natural consequence of any terminal illness. This change usually begins as a mild distaste for certain foods, progresses to a desire for only a few selected foods, and finally results in an almost complete lack of ability to eat. For both the patient and family, the loss of appetite can be one of the most distressing parts of an illness.

Food holds tremendous emotional, social, and cultural significance in our lives. The serving and sharing of food communicates strong messages about loving, caring, and friendship. When your loved one does not eat, not only are the chances of sharing the activity of eating lost, but fears about survival are common.

Family members often feel frustrated, helpless and afraid when patients express no desire to eat. The patient often senses their frustration and feels pressured to eat to please them. The following are ways that may help in coping with these changes.

- Accept the loss of appetite as an expected and normal part of the illness.

  a. Allow the patient to make selections of food and drinks.

    b. Offer small, frequent meals.
    c. Remember that softer foods are easier to chew and swallow.

- Offer different choices, but don't push.

- Find other ways of showing love and concern. Giving a massage or reading is often comforting.

- Recognize that this is a loss and like all losses that are a part of this illness, talking with others about it may make it less difficult.

- Know that prolonged use of intravenous fluids, tube feedings and other means of delivering artificial nutrition are usually not effective for persons with terminal illness and can serve to heighten the discomfort in a terminally ill person.

- If the patient is experiencing nausea (feeling sick to their stomach or as though they may vomit), tell your nurse so that medications can be placed in the home to address this immediately. If there are already medications in the home, administer at least 30 minutes prior to trying to eat to allow the medication to work as it should.

PAIN

Although not all hospice patients experience pain, the reality and the fear of pain are often major concerns. Pain causes not only physical discomfort, but also emotional discomfort. *The goal of Hospice is to minimize pain and at the same time maximize the quality of life*.

We believe:

- ➢ The person experiencing the pain knows the most about it and trust that pain is whatever the patient says it is.
- ➢ Pain is present whenever the patient says it is.
- ➢ Pain management will only work when the patient/family/caregiver understand and agree with the medication regimen. We must respect the patient's values, preferences and expressed needs.
- ➢ The pain regimen needs to be simple, with only enough of one or a combination of medicines to control the pain to the patient's satisfaction.
- ➢ The palliative approach to pain management means that the least invasive route of administration should be used.

Some patient and family concerns that we deal with on a daily basis:

- ➢ Tolerance: Tolerance develops when there is a need to increase the dose of the medication to achieve the same effect. This is an uncommon, yet normal result of opioid use and can be easily managed by appropriate titration of the medication. <u>*Tolerance does not equal addiction.*</u>
- ➢ Dependence: A predictable consequence of long term opioid administration, but can also occur with drugs other than narcotics. It is a physiologic accommodation to the presence of the drug which can cause withdrawal on cessation. Withdrawal symptoms are usually suppressed by gradual withdrawal of the opioid.
- ➢ Addiction: True addiction is a psychological issue in which opioids actually worsen the quality of a person's life. Use of the drug actually becomes the focus of life for the addict.

Multiple studies have proven that addiction is rare, occurring in less than 1% of patients using opioids for pain relief. (Margo McCaffrey, 1999)

- Numerous studies have shown that the side effects of opioids often diminish within 72 hours of initiation and with each titration (a change in dose).

The nurse will ask the patient and caregiver questions about any pain experienced and will use this information to work with the physician and pharmacist to develop a pain management plan. Included in this guide is a representation of the pain scale which is used by our staff, and also some verbal/non-verbal indicators of pain which you may notice and should report to the nurse. It is important to be honest about how often any pain is felt. If the patient is unable to rate their pain due to their condition, the staff will ask the caregiver to rate the level of comfort as best as possible. Many people report less pain than they are actually experiencing. Below are some reasons why this happens:

- Patients fear that an increase in medication dosage may mean the disease is worse so they deny the pain

- Some people are afraid that pain and the illness go hand in hand and that the pain must be tolerate

- Some religious beliefs hold pain as punishment or salvation

- Some cultures encourage people to experience pain in silence

- Some patients fear the use of strong pain medication will prevent relief when the pain gets worse in the future.

These reasons should be discussed openly, because they will influence the patient’s ability to share and evaluate his or her pain. The patient’s likes and dislikes are always considered when creating the plan of care. Patient’s experience different types of pain, and there are many ways they show signs of pain or tolerance. Some patients may moan, experience a rapid heart rate, or become restless. However, if this does not occur it does not mean the patient is not having pain. For these reasons, it is important for patients to speak honestly with their nurse or doctor about their experience of pain.

Usually, pain can be controlled with medication taken orally rather than by injection. Patients remain more comfortable when they take regular doses of medication around the clock. This prevents the patient from experiencing “peaks and valleys” of pain.

The nurse will work with the primary physician to determine the appropriate medication dosage and frequency in order to provide pain and symptom relief. Dosage and effects are monitored to avoid adverse side effects and will be adjusted according to the physician orders. Pain medication in the form of a rectal suppository, skin patch, or a medication under the tongue can also be used.

Remember:

- Some patients have no pain.
- Most patients are kept very comfortable if they take their medication on a regular schedule, around the clock.
- There is no reason to worry about addiction. Studies show that patients do not become addicted to the amount of medication needed to control pain.
- Do not be alarmed if the patient becomes drowsy or sleepy for a few days after starting a new medication or after increasing the dosage. This is not unusual; it takes time for the body to adjust to the new medication or dosage. Notify your Reliance Hospice nurse for reassurance or re-education that is medication related.
- Pain medications are given at a sufficient dose to control the patient's pain up to the maximum dose ordered by the physician. Medications should be taken according to the physician orders. Tell the nurse, or call the Reliance Hospice office (877) 659-5998, when pain medications are not working so we can take necessary measures to have the medication increased or changed by the physician.
- The nurse will count medications on a regular basis, and will contact the physician as necessary to reorder. Do not just stop taking your medications; a combination of several medications may be what is controlling pain.
- When a medication is no longer needed, it will be destroyed in accordance with applicable laws and Reliance Hospice protocols.

Complimentary alternatives which may also help to relieve pain and suffering along with medications are:

- Relaxation exercises to decrease tension.
- Gentle oil or lotion massage of painful areas.
- Therapeutic, compassionate, and healing touch techniques.
- Heating pads or ice packs applied to areas of pain or tenderness, and left on for no longer than 20 minutes. Heating pads should never be used without supervision.
- Deep heating local rubs to soothe nerve or muscle pain.
- Changes in position.
- Elevation of sore or swollen limbs on pillows positioned for comfort.
- Diversions such as quiet music, visitors, humor, reading aloud, or television to help focus attention away from suffering.

Reliance Hospice PAIN RATING SCALE

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0 1 2 3 4 5 6 7 8 9 10

NO PAIN MILD MODERATE SEVERE

Nonverbal Indicators of Pain

- Grimacing
- Inability to keep hands still
- Rocking
- Tightly shutting lips
- Massaging
- Thrashing
- Tightly closed eyes
- Immobilizing
- Biting
- Widely open eyes
- Blinking eyes
- Wrinkling forehead
- Sweating
- Moving from side to side
- Clenching teeth or grating teeth
- Guarding of a part of the body
- Pounding
- Tearing eyes
- Applying pressure, heat or cold
- Rubbing

Vocalization/Verbalization Behaviors Associated with Pain

- Moaning
- Groaning
- Grunting
- Sighing
- Gasping
- Crying
- Screaming
- Praying
- Counting
- Cursing
- Repeating nonsensical phrases

SKIN CARE and LIFTING & TURNING PATIENTS

It is important to try and keep the patient's skin in good condition. By the time a person becomes a Reliance Hospice patient, illness has often caused many changes in his/her body. The disease may cause weakness, loss of weight, low blood counts, and low nutritional intake, all of which can cause skin problems.   Dry skin, abrasions, and bedsores are just a few examples of what might occur.

When the patient remains in a chair or bed for an extended period of time it is important to take precautions. Some helpful steps to follow are:

- Frequent movement is important – if the patient is bed bound it is very important to turn frequently. A draw sheet can be used to assist with turning or lifting. The CHA or nurse will teach the caregiver how to use a draw sheet. To avoid injury it is very important to avoid pulling on the patient's shoulder and arms when turning the patient.
- Give pain medications as scheduled to make sure that movement is as pain free as possible.
- Keep the patient's skin clean and dry.
- Keep the bed linens dry and wrinkle-free.
- Apply lotion to the skin once or twice each day to prevent dryness.
- A small amount of Vaseline on the eyelids at bedtime makes discharge from the eyes less sticky and easy to remove from the eyes in the morning.
- To prevent pressure on the heels place pillows under the lower calves to keep the heels off the bed.
- Pad oxygen tubing to prevent pressure sores to ears

In spite of all efforts, a bedsore may still develop. If this occurs, the nurse will help determine the best way to treat the bedsore. As patients become weaker they begin to need help with getting out of a chair, or even turning in the bed. Some general rules for lifting and turning patients follow. Remember to use your leg muscles in order to take as much strain off your back as possible. Crouch or squat if you are able and keep your back straight. Work smoothly in your efforts, avoiding jerky movements which are more likely to cause a strained muscle.

HOW TO TURN A PATIENT TOWARD YOU

1. Assist the patient to flex his/her knees.

2. Slip your hand under the patient's shoulder and hips; assistant does the same.

3. On signal, move the patient to the other side of the bed.

4. Draw the patient's knees up and over to the free side.

5. Place your hands well in back of the shoulder and hips; draw the patient toward you.

6. Have your assistant place pillows behind the patient's back.

7. Adjust the patient's head, shoulders, and arms.

8. A draw sheet can be used to assist with turning or lifting.

9.

PATIENT RIGHTS, RESPONSIBILITIES, & CONDUCT

CUSTOMER FEEDBACK

HOME USE & DISPOSAL OF CONTROLLED SUBSTANCES

STANDARD PRECAUTIONS & APPROVED DISPOSAL METHODS FOR HOME-GENERATED BIOMEDICAL WASTE

NOTICE OF PRIVACY PRACTICES

PATIENT BILL OF RIGHTS, CONDUCTAND RESPONSIBILITIES

Patients have a right to be notified in writing of their rights and obligations before hospice care begins. Consistent with state laws, the patient's family or guardian may exercise the patient's rights when the patient is no longer able to do so. Hospice organizations have an obligation to protect and promote the rights of their patients.

As a patient, you have the right to:

1. Be informed of your rights in a manner which you understand.
2. Make informed decisions regarding proposed and ongoing care and services.
3. Choose whether or not to participate in research, investigational or experimental studies, or clinical trials.
4. Have your communication needs met.
5. Confidentiality of information, privacy and security.
6. Be fully informed, as evidenced by your written acknowledgement or by that of your appointed representative, of these rights and of all rules and regulations governing patient conduct, prior to or at time of admission.
7. Be involved in the care planning process.
8. Be fully informed of your medical condition, unless medically contraindicated, and to be afforded the opportunity to participate in your medical treatment.
9. Formulate advance directives.
10. Have an appropriate assessment and management of pain.
11. Keep and use personal clothing and possessions.
12. An environment that preserves dignity and contributes to a positive self-image.
13. Have unlimited contact with visitors and others.
14. Be fully informed, prior to or at time of admission of services available through Hospice, and related charges, including services not covered under Titles XVIII or XIX of the Social Security Act.
15. Refuse treatment to the extent permitted by law and to be informed of the medical consequences of such refusal.
16. Be advised of what hospice services are to be rendered and by what discipline, e.g., registered nurse, counselor, spiritual counselor, etc.
17. Be advised in advance of any changes in treatment, care, or services.
18. Be assured of confidential treatment of personal and clinical records and to approve or refuse their release to any individual outside the hospice, except in the case of transfer to another health facility, or as required by law or third-party payment contract.
19. Be treated with consideration, respect, and full recognition of dignity and individuality, including privacy in treatment and in care for personal needs.

20. Not be subjected to exploitation, verbal, sexual or physical abuse of any kind, and to be informed that corporal punishment is prohibited.

21. Be informed by the licensee of the provisions of the law regarding complaints and procedures for registering complaints confidentially, including, but not limited to, the address and telephone number of the local district office of the Department of Health Services.

22. Be informed of the provisions of the law pertaining to advanced directives, including but not limited to living wills, power of attorney for health care, withdrawal or withholding of treatment and/or life support.

23. Be assured the personnel who provide care are qualified through education and experience to carry out the services for which they are responsible.

24. Be informed of information addressing any beneficial relationships between the Hospice and referring entities, as well as, information addressing the Hospice ownership and control.

25. Be informed of information regarding investigation by the Hospice of complaints made by you, or your family, regarding your care and the Hospice's documentation of the existence of the complaint and the resolution of the complaint.

As a patient, you have the responsibility to:

1. Remain under a doctor's care while receiving agency services.
2. Inform the hospice of advance directives or any changes in advance directives, and provide the hospice with a copy.
3. Cooperate with your primary doctor, hospice staff, and other caregivers by providing information, asking questions and following instructions.
4. Advise the hospice of any problems or dissatisfaction you have with the care provided.
5. Notify the hospice of address or telephone number changes or when you are unable to keep appointments.
6. Provide a safe home environment in which care can be given. Conduct such that if the patient's or staff's welfare or safety is threatened, service may be terminated.
7. Obtain medications, supplies and equipment ordered by your physician if they cannot be obtained or supplied by the hospice.
8. Treat hospice personnel with respect and consideration.
9. Sign the required consents and releases for insurance billing, and provide insurance and financial records as requested.
10. Accept the consequences for any refusal of treatment or choice of non-compliance.
11. Advise the agency of any problem or dissatisfaction with our care, without being subject to discrimination or reprisal. The Hospice shall investigate all grievances; document the existence of the complaint and findings. Findings will be communicated to the patient/family.

Reliance Hospice patient-specific policies:

1. **Confidentiality Policy**
   The patient has the right to confidentiality, and as such, Reliance Hospice has a Statement of Confidentiality which all employees and volunteers are required to sign upon initial employment. Failure to comply with the Confidentiality policies could result in termination. In addition, all hospice contracts shall provide for patient confidentiality of the contracted services.

2. **Ethics Policy on Referrals**
   Reliance Hospice does not/shall not receive any financial benefit, when referring a patient to another organization, service or individual. We do not/will not engage in any activity that might be construed as enticement or inducement of business in accordance with Federal law.

MEDICAL TREATMENT DECISIONS:
HOSPICE CARE POLICIES AND PROCEDURES

Reliance Hospice respects your right to make your own medical treatment decisions. It is the policy of Reliance Hospice to inquire about the existence of previously executed Advance Directives and to offer all patients the opportunity to sign a Directive to Physicians and Family or Surrogates, and/or Do Not Resuscitate directive. Copies of these forms are available from Reliance Hospice. Whether or not a patient chooses to utilize an Advance Directive is a personal matter and will not be a condition of providing care or basis for discrimination for or against you.

Reliance Hospice will document in each person’s medical record whether or not an Advance Directive has been created. If an Advance Directive has been executed, you must provide a copy to reliance Hospice in order for your wishes to be followed.

CUSTOMER FEEDBACK

Reliance Hospice is committed to providing compassionate, quality care to our patients and families. We request you share any feedback, whether you consider it negative or positive. We believe that your feedback helps us to provide even better care to our patients and caregivers. Reliance Hospice has a policy which details our belief in your right to be informed of information regarding investigation by the Hospice of complaints made by you, or your family, regarding treatment of care and the Hospice’s documentation of the existence of the complaint and the resolution of the complaint. All you need to do is contact any staff member of Reliance Hospice. You may submit the concern in writing, or ask a staff member to document your concern on a Customer Service form. You may also simply call the office at **(866) 569-7922** and report your concern to a Manager or Director.

We provide notice to the public that if at any time you have questions, comments, or concerns about our services or patient safety you may call or write to our Administer or Director of Patient Care Services. Your services will not be diminished or discontinued if you or your family registers a complaint. Your complaint generally will be investigated within 24-72 hours of receipt. We will advise you of our findings and the action taken to resolve your complaint. Our toll free number is **(866) 569-7922.** Our address is: 74130 Country Club Drive Suite 103 Palm Desert, CA 92260.

Reliance Hospice is a Joint Commission Accredited Health Care Organization. If at any time you feel that your concerns have not been resolved through our office, you can contact the Joint Commission. The Joint Commission's Office of Quality Monitoring can be reached at 800-994-6610 or by emailing complaint@jcaho.org

Rehabilitation Act of 1973 Section 504

Summary: Section 504 prohibits discrimination on the basis of disability in programs and activities conducted by HUD or that receive financial assistance from HUD.

Purpose: In addition to its responsibility for enforcing other Federal statutes prohibiting discrimination in housing, HUD has a statutory responsibility under Section 504 to ensure that individuals are not subjected to discrimination on the basis of disability by any program or activity receiving HUD assistance. Section 504 charges HUD with enforcing the right of individuals to live in federally subsidized housing free from discrimination on the basis of disability. Further, Section 504 covers employment discrimination based on disability and requires HUD and HUD-assisted agencies to make reasonable accommodations for the known physical or mental limitations of an employee or qualified applicant. It covers all HUD programs except for its mortgage insurance and loan guarantee programs.

Eligible Customers: Any person with a disability who feels himself or herself a victim of discrimination in a HUD-funded program or activity may file a complaint with HUD under Section 504. During fiscal year (FY) 1996, HUD received 395 complaints, of which 229 were resolved. (These figures reflect combined complaints under Section 504 and Title II of the Americans with Disabilities Act of 1990.)

Application: Individuals may send complaints to a HUD Office of Fair Housing and Equal Opportunity (FHEO) in any of the 10 Fair Housing Enforcement Office hubs or to any of the 8 Fair Housing Enforcement Office Processing Centers or to the FHEO at HUD Headquarters.

Technical Guidance: Section 504 activities are authorized under the Rehabilitation Act of 1973. Field Offices and Headquarters FHEO staffprovide Section 504 technical assistance to recipients of HUD financial assistance and to consumers of HUD services. Program regulations--"Nondiscrimination Based on Handicap in Federally Assisted Programs and Activities and Federally Conducted Programs of the Department of Housing and Urban Development"--are at 24 CFR Parts 8 and 9. These activities are administered by HUD's Office of Fair Housing and Equal Opportunity. Contact Cheryl Kent at (202) 708-2333 or (202) 708-1734 (TTY).

For More Information: Government resources:
-- Fair Housing Information Clearinghouse, at 1-800-343-3442 or 1-800-290-1617 (TTY), supplies national and local information and links to fair housing resources inside and outside of Gov.
-- HUD Fair Housing Web Page provides information about the programs of the Office of Fair Housing and Equal Opportunity.

HOME USE AND DISPOSAL OF CONTROLLED SUBSTANCES

Reliance Hospice voluntarily adheres to a controlled drug reporting process.

1. Controlled substances will be distributed directly to the patient or his/her representative. The dispensing pharmacist will be responsible for monitoring the amount of drug issued and the length of time between renewals.

2. When a hospice patient no longer has a need for a controlled substance, the family will dispose of the medications with the nurse as witness. The nurse will instruct the family/caregiver to dispose of medications by dissolving them or crushing them and mixing them in cat litter (or other suitable substance) or by placing the medication in a wet disposable diaper to make it unusable and to then dispose of the cat litter or diaper in the trash. No medication should be flushed down the toilet. This instruction and the specific medications will be documented in clinical note.

3. The Case Manager or other staff member will document in the clinical record that the family disposed of medications or the patient and family/caregiver were instructed to dispose of medications and if they observed them performing this.

4. If the family/caregiver declines a visit upon the death of the patient, the family caregiver will be instructed to dispose of all medications in a manner that meets state and federal regulations. Staff member speaking with the patient will document that these instructions were given and that family took the responsibility to do so. The Coroner’s Office or other authorities may be contacted if you refuse to allow destruction of controlled substances.

Reliance Hospice staff will instruct Family / Caregiver on Disposal of Medications per Hospice P&P. Please ask your nurse for any questions or concerns.

STANDARD PRECAUTIONS AND APPROVED DISPOSAL METHODS FOR HOME-GENERATED BIOMEDICAL WASTE

Every year, biomedical waste (potentially infectious materials such as needles, blood products, etc.) is disposed of improperly, placing sanitary workers as well as the general public at risk for contracting dangerous diseases. Biomedical waste generated by individuals in their own home must be packaged and disposed of properly. The Centers for Disease Control and Prevention, a division of the U.S. Public Health Service, has published guidelines for health care workers handling human blood and other potentially infectious body fluids. These guidelines are termed Standard Precautions, and while intended for health care workers, *they are applicable to any person caring for another*.

As these guidelines are implemented by Reliance Hospice, human blood and all other human body fluids (e.g., wound drainage, urine, feces, and vomit) are considered potentially infectious, and appropriate precautions should be taken. Such precautions include the following:

- ■ Hand washing – Hands should be thoroughly washed before and after patient contact, and immediately if hands become soiled with blood or other body fluids. Hands should also be washed after removing gloves. **Washing hands before and after contact is the single most important means of preventing the spread of infection. Hands should be washed using soap and warm running water for at least 20 seconds.**
- ■ Gloves – Gloves should be worn whenever there is the possibility of contact with any body fluids. Gloves should always be worn if there are any cuts or sores present on the caregiver’s hands.
- ■ Gowns/Masks/Eye Protection – These are not usually needed, however their use should be considered when splashing of blood or other body fluids is likely.
- ■ Sharps – Sharp objects represent the greatest risk to infectious exposure. For purposes of the definition of sharps, we are including hypodermic needles, hypodermic syringes with attached needles, scalpel blades, razor blades, disposable razors, disposable scissors used in medical procedures, and IV stylets and rigid introducers. Immediately after use, dispose of sharps in a puncture-resistant container. **Do not bend, break, recap or remove the needle from the syringe.** Keep the disposal container in the room where the needles and syringes are used, but well out of the reach of children or visitors.
- ■ Spills of Blood/Body Fluids – Wearing gloves, wipe up excess material with disposable towels. Clean spill with soap and water. Disinfect contaminated area with a freshly prepared solution of household chlorine bleach diluted 1:10 bleach to water.
- ■ Laundry – wear gloves to handle clothing and bed linens soiled with blood or body fluids. If body fluid stains are present, put linens through cold wash cycle first. Then wash in HOT water with 1 cup of bleach added to the wash cycle.
- ■ Infectious waste – Flush all liquid waste down the toilet. Tissues or other FLUSHABLE items containing body fluids may also be flushed. NONFLUSHABLE materials containing body fluids (e.g., wound dressings, diapers, paper towels) should be placed in a plastic bag and tied securely. This bag should then be placed in a second bag (double bag technique) and should be closed securely.
- ■ Disposal Tips –Reliance Hospice suggests following the guidelines provided by the United States Environmental Protection Agency.

For Sharps: Place all sharps listed above into a hard plastic or metal container with a screw-on lid or tightly secured lid. The container MUST BE PUNCTURE PROOF. Before discarding, be sure to reinforce the lid with heavy duty tape. **Do not put sharp objects in any container you plan to recycle, and do not use clear plastic or glass containers. Reliance Hospice can provide you with a puncture proof container for sharps.**

For Non-Sharps: Place soiled bandages, disposable sheets, medical gloves, and other contaminated non-sharp material into a plastic bag. Secure the top of the bag. Again place within a second bag, secure tightly and place the bag into a garbage can with your other trash.

Disposal Tips for Home Health Care

YOU can help prevent injury, illness, and pollution by following some simple steps when you dispose of the sharp objects and contaminated materials you use in administering health care in your home. You should place:

- **Needles**
- **Syringes,**
- **Lancets, and**
- **Other sharp objects**

In a hard-plastic or metal container with a screw-on or tightly secured lid.

A coffee can will do, but you should be sure to reinforce the plastic lid with heavy-duty tape. Do not put sharp objects in any container that will be recycled or returned to a store. Do not use glass or clear plastic containers. Finally, make sure that you keep containers with sharp objects out of the reach of young children.

We also recommend that:

- ***Soiled bandages,***
- ***Disposable sheets, and***
- ***Medical gloves***

be placed in securely fastened (double) plastic bags before you put them in the garbage can with your other trash.

THIS NOTICE DESCRIBES HOW MEDICAL INFORMATION ABOUT YOU MAY BE USED AND DISCLOSED AND HOW YOU CAN GET ACCESS TO THIS INFORMATION.

PLEASE REVIEW IT CAREFULLY!

EFFECTIVE SEPTEMBER 23, 2013

I. USE AND DISCLOSURE OF HEALTH INFORMATION

Reliance Hospice may use your health information (information that constitutes protected health information as defined in the Privacy Rule of the Administrative Simplification provisions of the Health Insurance Portability and Accountability Act (HIPAA) of 1996) for purposes of providing you treatment, obtaining payment for your care and conducting health care operations. The Hospice has established policies to guard against unnecessary disclosure of your health information.

THE FOLLOWING IS A SUMMARY OF THE CIRCUMSTANCES UNDER WHICH, AND PURPOSES FOR WHICH, THE LAW PERMITS YOUR HEALTH INFORMATION TO BE USED AND DISCLOSED:

To Provide Treatment. The Hospice may use your health information to coordinate care within the Hospice and with others involved in your care, such as your attending physician, members of the Hospice interdisciplinary team and other health care professionals who have agreed to assist the Hospice in coordinating care. For example, physicians involved in your care will need information about your symptoms in order to prescribe appropriate medications. The Hospice also may disclose your health care information to individuals outside of the Hospice involved in your care including family members, caregivers, clergy who you have designated, pharmacists, suppliers of medical equipment or other health care professionals.

To Obtain Payment. The Hospice may use and disclose your health information to collect payment from third parties for the care you receive from the Hospice. For example, the Hospice may be required by your health insurer to provide information regarding your health care status so that the insurer will reimburse you or the Hospice. For this purpose, your health information may be used and disclosed on invoices, correspondence and other communications with your health insurer. The Hospice also may need to obtain prior approval from your insurer and may need to use and disclose health information to explain to the insurer your need for hospice care and the services that will be provided to you.

To Conduct Health Care Operations. The Hospice may use and disclose health information for its own operations in order to facilitate the function of the Hospice and as necessary to provide quality care to all of the Hospice's patients. Health care operations include such activities as:

- Quality assessment and improvement activities
- Activities designed to improve health or reduce health care costs
- Protocol development, case management and care coordination
- Contacting health care providers and patients with information about treatment alternatives and other related functions that do not include treatment
- Professional review and performance evaluation
- Training programs including those in which students, trainees or practitioners in health care learn under supervision
- Training of non-health care professionals
- Accreditation, certification, licensing or credentialing activities
- Review and auditing, including compliance reviews, medical reviews, legal services and compliance programs
- Business planning and development including cost management and planning related analyses and formulary development
- Business management and general administrative activities of the Hospice
- Fundraising for the benefit of the Hospice: A PATIENT MAY OPT OUT OF THEIR HEALTH INFORMATION BEING USED FOR FUNDRAISING PURPOSES, WITHOUT ANY RECOURSE OR COST TO THE PATIENT, BY CONTACTING THE HOSPICE'S DESIGNATED PRIVACY OFFICER.

For example the Hospice may use your health information to evaluate its staff performance, combine your health information with other Hospice patients in evaluating how to more effectively serve all Hospice patients, disclose your health information to Hospice staff and contracted personnel for training purposes, use your health information to contact you as a reminder regarding a visit to you, or contact you as part of general fundraising and community information mailings (unless you tell us you do not want to be contacted).

For Appointment Reminders. The Hospice may use and disclose your health information to contact you as a reminder that you have an appointment for a visit.

For Treatment Alternatives. The Hospice may use and disclose your health information to tell you about or recommend possible treatment options or alternatives that may be of interest to you.

THE FOLLOWING IS A SUMMARY OF THE CIRCUMSTANCES UNDER WHICH, AND PURPOSES FOR WHICH, YOUR HEALTH INFORMATION MAY ALSO BE USED AND DISCLOSED WITHOUT YOUR PRIOR AUTHORIZATION OR CONSENT, UNLESS SUCH DISCLOSURE IS FURTHER RESTRICTED OR LIMITED BY CALIFORNIA LAW:

When Legally Required. The Hospice will disclose your health information when it is required to do so by any Federal, State or local law.

When There Are Risks to Public Health. The Hospice may disclose your health information for public activities and purposes in order to:

- Prevent or control disease, injury or disability, report disease, injury, vital events such as birth or death and the conduct of public health surveillance, investigations and interventions
- Report adverse events, product defects, to track products or enable product recalls, repairs and replacements and to conduct post-marketing surveillance and compliance with requirements of the Food and Drug Administration
- Notify a person who has been exposed to a communicable disease or who may be at risk of contracting or spreading a disease
- Notify an employer about an individual who is a member of the workforce as legally required

To Report Abuse, Neglect Or Domestic Violence. The Hospice is allowed to notify government authorities if the Hospice believes a patient is the victim of abuse, neglect or domestic violence. The Hospice will make this disclosure only when specifically required or authorized by law or when the patient agrees to the disclosure.

To Conduct Health Oversight Activities. The Hospice may disclose your health information to a health oversight entity for activities including audits, civil administrative or criminal investigations, inspections, licensure or disciplinary action. The Hospice, however, may not disclose your health information if you are the subject of an investigation and your health information is not directly related to your receipt of health care or public benefits.

In Connection With Judicial And Administrative Proceedings. The Hospice may disclose your health information in the course of any judicial or administrative proceeding in response to an order of a court or administrative tribunal as expressly authorized by such order or in response to a subpoena, discovery request or other lawful process, but only when the Hospice makes reasonable efforts to either notify you about the request or to obtain an order protecting your health information.

For Law Enforcement Purposes. As permitted or required by State law, the Hospice may disclose your health information to a law enforcement official for certain law enforcement purposes as follows:

- As required by law for reporting of certain types of wounds or other physical injuries pursuant to a court order, warrant, subpoena or summons or similar process
- For the purpose of identifying or locating a suspect, fugitive, material witness or missing person
- Under certain limited circumstances, when you are the victim of a crime
- To a law enforcement official if the Hospice has a suspicion that your death was the result of criminal conduct including criminal conduct at the Hospice
- In an emergency in order to report a crime

To Coroners And Medical Examiners. The Hospice may disclose your health information to coroners and medical examiners for purposes of determining your cause of death or for other duties, as authorized by law.

To Funeral Directors. The Hospice may disclose your health information to funeral directors consistent with applicable law and if necessary, to carry out their duties with respect to your funeral arrangements. If necessary to carry out their duties, the Hospice may disclose your health information prior to and in reasonable anticipation of your death.

For Organ, Eye Or Tissue Donation. The Hospice may use or disclose your health information to organ procurement organizations or other entities engaged in the procurement, banking or transplantation of organs, eyes or tissue for the purpose of facilitating your wishes regarding the donation and transplantation.

For Research Purposes. The Hospice may, under very select circumstances, use your health information for research. Before the Hospice discloses any of your health information for such research purposes, the project will be subject to an extensive approval process.

In the Event of A Serious Threat To Health Or Safety. The Hospice may, consistent with applicable law and ethical standards of conduct, disclose your health information if the Hospice, in good faith, believes that such disclosure is necessary to prevent or lessen a serious and imminent threat to your health or safety or to the health and safety of the public.

For Specified Government Functions. In certain circumstances, the Federal regulations authorize the Hospice to use or disclose your health information to facilitate specified government functions relating to military and veterans, national security and intelligence activities, protective services for the President and others, medical suitability determinations and inmates and law enforcement custody.

For Worker's Compensation. The Hospice may release your health information for worker's compensation or similar programs.

THE FOLLOWING IS A SUMMARY STATEMENT OF THE CIRCUMSTANCES UNDER WHICH YOUR AUTHORIZATION IS NEEDED TO USE OR DISCLOSE HEALTH INFORMATION:

ANY USES AND DISCLOSURES OF YOUR HEALTH INFORMATION NOT DESCRIBED IN THIS NOTICE CAN AND WILL BE MADE ONLY WITH YOUR WRITTEN AUTHORIZATION. If you or your representative authorizes the Hospice to use or disclose your health information, you may revoke that authorization in writing at any time by contacting the Privacy Officer.

II. YOUR RIGHTS WITH RESPECT TO YOUR HEALTH INFORMATION

You have the following rights regarding your health information that the Hospice maintains:

Right to request restrictions. You may request restrictions on certain uses and disclosures of your health information. You have the right to request a limit on the Hospice's disclosure of your health information to someone who is involved in your care or the payment of your care. However, the Hospice is not required to agree to your request unless a request for restriction regards a disclosure whose purpose is for the carrying out of payment or health care operations and is not otherwise required by law, or the protected health information requested to be restricted pertains solely to a health care item or service for which a patient, or person other than the health plan on behalf of the patient, has paid the hospice in full. If you wish to make a request for restrictions, please contact the Hospice Privacy Officer.

Right to receive confidential communications. You have the right to request that the Hospice communicate with you in a certain way. For example, you may ask that the Hospice only conduct communications pertaining to your health information with you privately with no other family members present. If you wish to receive confidential communications, please contact the Hospice Privacy Officer*.* The Hospice will not request that you provide any reasons for your request and will attempt to honor your reasonable requests for confidential communications.

Right to inspect and copy your health information. You have the right to inspect and copy your health information, including billing records with few restrictions as required by law. You also have a right to request an electronic copy of any of your health information that is electronically held by the hospice. A request to inspect and copy records containing your health information may be made to the Hospice Privacy Officer*.* If you request a copy of your health information, the Hospice may charge a reasonable fee for copying and assembling costs associated with your request. Should we deny you the ability to inspect or copy your health information as allowed under applicable law, you have the legal right to a review of the denial.

Right to amend health care information. You, or your representative, have the right to request that the Hospice amend your records, if you believe that your health information is incorrect or incomplete. That request may be made as long as the information is maintained by the Hospice. A request for an amendment of records must be made in writing to the Hospice Privacy Officer. The Hospice may deny the request if it is not in writing or does not include a reason for the amendment. The request also may be denied if your health information records were not created by the Hospice, if the records you are requesting are not part of the Hospice's records, if the health information you wish to amend is not part of the health information you or your representative are permitted to inspect and copy, or if, in the opinion of the Hospice, the records containing your health information are accurate and complete.

Right to an accounting. You or your representative have the right to request an accounting of disclosures of your health information made by the Hospice for certain reasons, including reasons related to public purposes authorized by law and certain research. The request for an accounting must be made in writing to the Hospice Privacy Officer*.* The request should specify the time period for the accounting starting on or after April 14, 2003. Accounting requests may not be made for periods of time in excess of six (6) years. The Hospice would provide the first accounting you request during any 12-month period without charge. Subsequent accounting requests may be subject to a reasonable cost-based fee.

Right to a paper copy of this notice. You, or your representative, have a right to a separate paper copy of this Notice at any time even if you or your representative have received this Notice previously. To obtain a separate paper copy, please contact the Hospice Privacy Officer*.*

III. DUTIES OF THE HOSPICE

The Hospice is required by law to maintain the privacy of your health information and to provide to you and your representative this Notice of its duties and privacy practices and to notify you of any breaches of unsecured health information that may or may not directly affect you. The Hospice is required to abide by the terms of this Notice as may be amended from time to time. The Hospice reserves the right to change the terms of its Notice and to make the new Notice provisions effective for all health information that it maintains. If the Hospice changes its Notice, the Hospice will provide a copy of the revised Notice to you or your appointed representative via U.S. mail. You or your personal representative has the right to express complaints to the Hospice and to the Secretary of Department of Health and Human Services (DHHS) if you or your representative believe that your privacy rights have been violated. Any complaints to the Hospice should be made in writing to the Hospice Privacy Office listed below*.* The Hospice encourages you to express any concerns you may have regarding the privacy of your information. You will not be retaliated against in any way for filing a complaint.

IV. CONTACT PERSON

The Hospice has designated a Privacy Officer as its contact person for all issues regarding patient privacy and your rights under the Federal privacy standards. You may contact the Reliance Privacy Officer listed below. **IF YOU HAVE ANY QUESTIONS REGARDING THIS NOTICE, PLEASE CONTACT THE RELIANCE PRIVACY OFFICER:**

Palm Desert Program: Mrs. Elena Verdugo, Reliance Hospice Privacy Officer 74130 Country Club, Suite 103, Palm desert, CA 92260. Phone at 760-423-6924

SAFETY PRECAUTIONS

EARTHQUAKE

BEFORE AN EARTHQUAKE

How well you, your family and your home survive an earthquake often depends upon how well you prepare beforehand. Develop a family and neighborhood earthquake plan. The following checklist will help you get started:

- Prepare an emergency kit of food, water, and supplies including a flashlight, portable battery-operated radio, batteries, medicines, first aid kit, money and clothing.
- Know the safe spots in each room – under sturdy tables, desks, or against interior walls.
- Know the danger spots – near windows, mirrors, hanging objects, fireplaces, and tall, unsecured furniture.
- Conduct practice drills so you and your family know the safe locations in your home.
- Decide how and where your family will reunite if separated during a quake.
- Choose an out-of-state friend or relative who family members can call after the quake to report their whereabouts and conditions.
- Learn first aid and CPR (cardiopulmonary resuscitation).
- Learn how to shut off gas, water, and electricity in case the lines are damaged. SAFETY NOTE: Do not attempt to relight the gas pilot. Call the utility company.
- Check chimneys, roofs, walls and foundations for stability. Make sure your house is bolted to its foundation.
- Secure your water heater and major appliances as well as tall, heavy furniture, hanging plants, mirrors, and picture frames – especially those over beds.
- Keep breakables, heavy objects, flammable or hazardous liquids such as paints, pest sprays and cleaning products, in secured cabinets or on lower shelves.
- Organize your neighborhood to be self-sufficient after a quake.

DURING AN EARTHQUAKE

- If indoors, stay there. Get under a desk or table or stand in a corner.
- If outdoors get into an open area away from trees, buildings, walls and power lines.
- If in a high-rise building, stay away from windows and outside walls. Get under a table. Do not use elevators.
- If driving, pull over to the side of the road and stop. Avoid overpasses and power lines. Stay insider your car until the shaking is over.
- If in a crowded public place, do not rush for the doors. Crouch and cover your head and neck with your hands and arms.

AFTER AN EARTHQUAKE

Unless there is an immediate, life-threatening emergency, do not attempt to use the telephone. After a quake, be sure to:

- Check for gas and water leaks, broken electrical wiring or sewage lines. If there is damage, turn the utility off at the source and immediately report gas leaks to your utility company.
- Check for downed power lines; warn others to stay away.
- Check your building for cracks and damage, including the roof, chimneys and foundation.
- Turn on your portable radio for instructions and news reports. For your own safety, cooperate fully with public safety officials and follow instructions.
- Do not use your vehicle unless there is an emergency. Keep the streets clear for emergency vehicles.
- Be prepared for aftershocks.
- Stay calm and lend a hand to others.
- If you evacuate, leave a message at your home telling family members and others where you can be found.

CAN YOU GO IT ALONE FOR THREE DAYS?

The first 72 hours after an earthquake are critical. Electricity, gas, water, and telephones may not be working. In addition, public safety services such as police and fire departments will be busy handling serious crises. You should be prepared to be self-sufficient – able to live without running water, electricity and/or gas, and telephones – for at least three days following a quake. To do so, keep on hand in a central location, the following:

- **Food**. Enough for 72 hours, preferably one week.
- **Water.** Enough so each person has one gallon a day for 72 hours, preferably one week. Store in airtight containers and replace it every six months. Store disinfectants such as iodine tablets or chlorine bleach, eight drops per gallon, to purify water if necessary.
- **First aid kit.** Make sure it’s well stocked, especially with bandages and disinfectants.
- **Fire extinguisher.** Your fire extinguisher should be suitable for all types of fires. Teach all family members how to use it.
- **Flashlights with extra batteries.** Keep flashlights beside your bed and in several other locations. DO NOT use matches or candles after an earthquake until you are certain there are no gas leaks.
- **Portable radio with extra batteries.** Most telephones will be out of order or limited to emergency use. The radio will be your best source of information.
- **Extra blankets, clothing, shoes and money.**
- **Alternate cooking sources.** Store a barbecue or camping stove for outdoor camping. CAUTION: Ensure there are no gas leaks before you use any kind of fire as a cooking source and do not use charcoal indoors.
- **Special items.** Have at least one week’s supply of medications and food for infants and those with special needs. Don’t forget pet food.
- **Tools.** Have an adjustable or pipe wrench for turning off gas and water.

EMERGENCY PREPAREDNESS

When patients are at home, it is especially important that you and your family prepare for emergencies in advance. Emergencies can include natural disasters, such as tornadoes, earthquakes, and ice storms. They can also include man-made disasters such as chemical spills.

When a community experiences an emergency situation, it is not uncommon to experience:

- Interruptions in electric power
- Phone lines may be down
- Water may not be drinkable
- Roads can become impassable

Some General Guidelines:

- Discuss with family members and friends your plans for emergency preparedness in advance of the emergency situation
- Keep a list of disaster and emergency phone numbers and know how to contact these if assistance is needed
- It is important to remain calm when an emergency occurs
- Be sure to wear shoes before exiting your home
- Keep a flashlight and portable radio with fresh batteries in a convenient place
- Keep at least one week's supply of canned or dried food that can be prepared without cooking along with a manual can opener
- Store drinking water in clean, closed containers
- Keep backup batteries for any device that could create a life threatening situation if not working
- Know how to use manual back-up systems provided to you
- Know how to maintain and move equipment that is heavy if it is life-sustaining
- Keep items together in a disaster preparedness kit should you need to evacuate your home

If your home should be in a disaster area:

- Check gas, water, and sewage for breaks and leaks
- Do not use electrical equipment in wet areas until it has been checked
- Check for fallen electrical lines
- Check for building damage prior to entering your home
- Do not eat food that has become wet or contaminated

Know how to:

- Turn off the gas, water and electricity to your home
- Reunite with your family should you become separated at a pre-designated place

Numbers to know:

Reliance Hospice has a nurse on call 24 hours a day/7 days a week.

Phone: (866-569-7922)

911 is the Emergency Services Number

BASIC HOME ENVIRONMENT SAFETY

It is sometimes difficult, when caring for a loved one, to know or be aware of safety precautions. Reliance Hospice is concerned about the safety of our patients and we offer the following tips to help minimize or prevent safety related accidents.

ELECTRICAL SAFETY

Extension cords should be placed beneath rugs and furniture or should be securely fastened to the wall or floor. They should never be allowed to lie loosely on the floor or hand across a pathway. Extension cords should never be overloaded. Use multiple outlet adapters if necessary. Replace frayed cords. Unused electrical equipment should be unplugged.

TELEPHONE

1. Have at least one phone accessible in the event of an accident. Keep it close by at all times. Other arrangements should be made for emergencies if no telephone is available.
2. The Hospice number and other emergency numbers should be posted on or near the phone.

RUGS, RUNNERS AND MATS

1. Loose rugs, runners and mats should be secured to the floor with double-sided adhesive tape or removed if possible.
2. Carpet edges should be tacked down.
3. Worn, torn or frayed carpeting should be repaired, replaced or removed.

BATHROOMS

1. Tubs and showers should have a textured surface or non-skid mats or strips to avoid falls.
2. Grab bars to assist in transferring should be installed in tub, shower, and toilet areas.
3. Shower chairs are helpful if a patient is weak and still wants the comfort of a shower.
4. Check the water temperature before entering the tub or shower.
5. A night-light should be used in the bathrooms.

STAIRS, HALLWAYS, PASSAGEWAYS

1. Stairs should have sturdy, well-secured handrails on both sides.
2. Stairs, hallways, passageways between rooms should be well lit and free of clutter.
3. Avoid using stairs while wearing only socks or smooth soled shoes.

MEDICATION SAFETY

Your medications are ordered just for you. It is important that no one but you take these medications!

1. Take medications as directed and ask your hospice nurse what to do with medicines you no longer use.
2. Store your medications in a safe place away from children and visitors.
3. If you think someone else is taking your medication, or if any of your medications are missing, talk to a member of your hospice team.

FIRE SAFETY

1. Fire regulations recommend one smoke detector on every level of your home.
2. Develop an evacuation plan to exit the home in the event of fire. Prioritize family members who are dependent, non-ambulatory or will require assistance.
3. Establish clear pathways to all exits. DO NOT BLOCK EXITS with furniture or boxes.
4. HAVE KEYS ACESSIBLE near dead bolt locked doors.
5. DO NOT smoke when oxygen is in use.

DOMESTIC VIOLENCE

If for any reason you feel unsafe with a spouse, caregiver or other threatening persons, call 911 for help in an emergency. DON'T ALLOW someone's abusive behavior to stop you from getting safe, comfortable care. Your Reliance Hospice team is responsible for reporting any suspected abuse according to the law.

SAFETY RULES FOR OXYGEN USE

A patient may, at some point in his/her illness, require therapy to assist in breathing comfort. If oxygen therapy is needed, the Hospice nurse, based upon the doctor's order, will assist in contacting the medical supply company. The medical supply company will then deliver the oxygen to the home and instruct the patient and caregiver on its usage, including how to clean the filter on the concentrator and how to fill the humidifier bottle. The most common way to receive oxygen therapy is by nasal cannula and the cannula should be replaced when soiled and at a minimum of every 2 months. The prongs on the cannula must be in the patient's nose and kept clean with a soft, moist cloth. Even though a patient may be mouth breathing, oxygen via the nasal cannula is still being inhaled.

NOTE: If breathing problems continue, call the Hospice office for further professional guidance.

1. Keep oxygen containers at least ten feet away from any flames, including matches, cigarette lighters, candles, gas stoves and any other flame source.

2. There should be no smoking in the room where oxygen is being used.
   DO NOT SMOKE WHEN USING OXYGEN!

3. Keep all electrical equipment ten feet from oxygen equipment if possible. (Electrical equipment, which gets hot or throws sparks, including radios, televisions, electric razors, and DON'T FORGET FRICTION TOYS OR TOYS WHICH SPARK.)

4. Keep oxygen concentrators at least 12 inches from the wall. Do not store in small closets.

5. All equipment should be properly grounded with a 3-prong plug. Do not use extension cords or plug multipliers.

6. Do not attempt to lubricate oxygen equipment and never handle any oxygen equipment with oily hands or rags.

7. Do not use aerosol cans near oxygen.

8. Do not use Vaseline in your nose when using a nasal cannula.

9. Cylinders, when used, must always be in carriers.

10. Cylinders should not be left in areas over 125 degrees F, or below 32 degrees F.

11. Never set the flow rate higher or use oxygen more than your doctor has ordered. Too much oxygen can damage your lungs and even slow your breathing.

12. Your oxygen tank will not explode or burn. Oxygen does not burn, but it does help other things burn faster.

13. Do not tamper with your equipment or try to fix it. Notify our office or the supplier immediately with any problems.

14. If you have any questions about appropriate use of equipment or transporting it, please contact our office.

15. Set up a fire escape route. Have a working smoke detector and fire extinguisher.

EQUIPMENT IN HOME

General Equipment Guidelines:

- Be sure to understand how to use the equipment prior to use.

- Read all safety precautions and warnings associated with the equipment and its use in the home.

- Do not let someone else use your equipment.

- If a piece of the equipment does not function properly, do not use it until it has had a safety check.

- Maintain all equipment according to its instructions.
- Periodically, examine your equipment for signs of wear, damage or other potential problems.
- Do not use equipment if the plug or cord looks damaged.
- Do not plug into an overloaded circuit.

NOTE: These guidelines are for informational purposes only. These guidelines are not intended to replace the instructions provided by the supplier; therefore, it is recommended that you read all safety precautions and warnings associated with the equipment prior to use.

DRUG CLASS AND FOOD INTERACTION
PATIENT TEACHING TOOL

This information is intended for general information only. Refer to your physician or pharmacist for specific instructions.

A. **ANTIANGINAL**

What it does: Relaxes and dilates coronary vessels, dilates or opens blood vessels in the heart to increase oxygen to the heart muscles.

What to watch for: Constant dull headache, lightheadedness if you stand up too rapidly, nausea, increase or decrease in heart rate.

Pastes: Absorbed through skin – best after bath or shower, to dry skin. Be sure to remove old patch. Best place to put it is on the chest, abdomen, or upper arms.

Sublingual: Take under your tongue every five minutes – not more than a total of three pills for each chest pain episode or as directed by your physician. Keep pills in bottle, and do not mix with other pills. Refill every six months and discard old pills. Pill is still potent if it burns or tingles when placed under the tongue.

Food Interaction: None known at this time.

B. **ANTIARTHRITIC/ANTIGOUT**

What it does: Decreases inflammation, promotes excretion of uric acid.

What to watch for: Skin rash, upset stomach. Take with food to minimize stomach distress.

Food Interaction: None known at this time.

C. **ANTIDIARRHEAL**

What it does: Decreases GI tract mobility and stool's fluid content. Stops diarrhea.

What to watch for: Dizziness, drowsiness, dry mouth, urinary retention, rash, constipation. DO NOT exceed recommended dosage.

Food Interaction: None known at this time.

D. **ADRENERGIC (SYMPATHOMIMETIC) (PRESSOR AGENTS)**

What it does: Stimulates heart muscle. Increases oxygen consumption, increases blood pressure, reduces peripheral circulation, bronchodilation.

What to watch for: Throbbing headache, nervousness, anxiety, dizziness, urinary retention. DO NOT change dose or frequency of medication.

Food Interactions: Limit caffeine.

E. **STERIODS**

What it does: Used for severe inflammation or immunosuppression. Decreases inflammation and suppresses immune response.

What to watch for: GI upset – take with meals. Long term – peptic ulcers, moon face, acne. DO NOT suddenly stop medication without doctor's advice.

Food Interaction: May need to decrease sodium and concentrated sweets intake. Avoid grapefruit juice.

F. **ANALGESIC**

What it does: Decreases inflammation, reduces fever, decreases pain.

What to watch for: Upset stomach – always take with food. Store in tightly covered, light-resistant containers.

Food Interaction: No alcohol.

G. **ANTIARRHYTHMICS**

What it does: Helps heart beat regularly.
What to watch for: Dry mouth, lightheadedness, ringing in ears, changes in urination (burning or inability), nausea, headache. Herbs: Limit aloe, foxglove, hawthorn, and avoid St. John's Wort.
Food Interaction: None known at this time.

H. **ANTIBIOTICS**

What it does: Kills or inhibits growth of infectious agents.
What to watch for: Diarrhea, skin rash nausea, vomiting. Take as ordered – either with food or on an empty stomach. IMPORTANT to complete entire prescribed course of medication even if you feel well.
Food Interaction: Ampicillin: Do not take with acidic fruit, vegetable juice or carbonated beverages. Erythromycin: Do not take grapefruit juice at the same time. Cipro: Limit caffeine.

I **ANTICHOLINERGICS**

What it does: Increases peristalsis of GI tract. Dilates and paralyzes pupils.
What to watch for: Flushing, abdominal cramps, dry mouth and eyes. Nausea, vomiting, constipation, mild tachycardia.
Food Interaction: None known at this time.

J. **ANTICOAGULANTS/ANTIPLATELETS/THROMBOLYTICS**

What it does: Increases clotting time. Decreases vitamin K dependent clotting factor production by liver.
What to watch for: Bleeding gums, blood tinged urine, bloody nose, bruises. DO NOT take aspirin while on anticoagulants. Avoid Supplements/Herbs: garlic, ginger, ginkgobiloba, vitamins C, E, A.
Food Interaction: (Coumadin, Warfarin) Consistent intake of vitamin K containing foods essential (i.e. green leafy vegetables, liver, avocado, no more than 2 oz onions)

K. **ANTICONVULSANTS**

What it does: Controls seizures.
What to watch for: Double vision, headaches, dizziness, speech incoordination, drowsiness, rash. Avoid alcohol. Take as ordered – DO NOT discontinue.
Food Interaction: None known at this time. Dilantin: If in tube feeding, contact pharmacist or dietician.

L. **ANTIDEPRESSANTS**

What it does: Modifies mood; changes activity level.
What to watch for: Dry mouth, lightheadedness if you stand up too quickly, headache, confusion, nausea, vomiting, constipation.
Food Interaction: (Ex: Nardil) Avoid high tryamine foods (refer to pressure agent food list on page 4) during the two weeks after ending doses. Herbs: Avoid ginseng, St. John's Wort, aged cheeses (Cheddar, Bleu, Gorgonzola, Stilton), aged meats (such as salami and mortadella), soy sauce, fermented soya bean, soya bean paste, tofu/fermented bean curd, miso soup, fava beans, snow pea or broad bean pods (contain dopamine), sauerkraut, kimchee, tap beer, Korean beer, concentrated yeast extracts (Marmite), banana peel, all casseroles made with aged cheese.

M. **ANTIDIABETIC ORAL**

What it does: Oral medication for diabetes mellitus. Helps make your body use insulin more effectively.
What to watch for: Signs of hypoglycemia (*low blood sugar*). Weak, shaky, sweating, dizziness, hunger, headache, nausea, *(high blood sugar*): Thirst, increased urination, abdominal pain, drowsiness, nausea, difficulty breathing.

Food Interaction: Follow prescribed diabetic diet.

ANTIDIABETIC INSULIN
What it does: Treats diabetes mellitus by replacing body's insulin in diabetic patients.
What to watch for: Signs of hypoglycemia or hyperglycemia.
Food Interaction: Follow prescribed diabetic diet.

N. ANTIHISTAMINES

What it does: Reduce itching, edema, smooth muscle contraction. Specific types – H2 blocker: reduces gastric secretion.
What to watch for: Drowsiness, dizziness, weakness, blurred vision, red and dry skin, upset stomach. Take with food or water to minimize stomach distress.
Food Interaction: None known at this time.

O. ANTIHYPERTENSIVES

What it does: Lowers blood pressure. Helps decrease workload of heart.
What to watch for: Dizziness, lightheadedness when getting up, headache, stomach upset, loss of taste, fatigue, insomnia. Take with food to minimize stomach distress.
Food Interaction: Observe low sodium diet. Limit caffeine and alcohol consumption.

P. GI TRACT DRUGS/H2 ANTAGONIST

What it does: Decrease gastric acid secretion or protect ulcerated surface by forming a barrier (Carafate).
What to watch for: Mild diarrhea, headache, rash, sweating, nausea, malaise, constipation. NOTE: Separate antacids and these medications by one hour.
Food Interaction: None known at this time.

Q. ANTIPARKINSON

What it does: Relaxes smooth muscle, blocking agent to reduce symptoms.
What to watch for: Dry mouth, dizziness, nervousness, agitation, blurred vision, urinary retention.
Food Interaction:Effectiveness decreased by high protein diet. Take with low protein or non acid juice. Avoid fava beans and vitamin B6 supplementation.

R. ANTIPYRETICS

What it does: Used to treat fever
Very similar to analgesics.

S. SPASMOLYTICS

What it does: Relaxes smooth muscle of bronchial airways or urinary tract.
What to watch for: Rapid heart rate, restlessness, dizziness, nausea, vomiting, poor appetite, dry mouth, blurred vision, and rash. DO NOT crush or dissolve slow-release products.
Food Interaction: None known at this time.

T. CARDIAC GLYCOSIDES

What it does: Improves the strength of heart contractions.
What to watch for: Anorexia, upset stomach, diarrhea, headache, fatigue, skin rash, irregular heart rate. Check pulse before taking medication. DO NOT TAKE if pulse is below __________.
Food Interaction: Take 30 minutes before meals as absorption decreases with food. Bran fiber decreases absorption. Limit use of herbal teas and licorice.

U. **CHOLINERGICS**

What it does: 1) Stimulates intestine and bladder contraction. Increases smooth muscle tone. 2) To lower intraocular pressure in glaucoma.

What to watch for: Flushing of skin, tearing, stomach-upset. Sustained papillary contraction, pain in eye, blurred vision, headaches, twitching, painful brow.

Food Interaction: None known at this time.

V. **DIURETICS**

What it does: Water pill to rid body of excess fluid to reduce heart's work. May also decrease blood pressure.

What to watch for: Leg cramps, vomiting, dizziness, weakness and mental confusion – if these occur – CALL YOUR DOCTOR.

Food Interaction: Adequate potassium foods and limit sodium. Avoid natural licorice.

W. **ELECTROLYTE REPLENISHERS**

What it does: Supplements lost electrolytes.

What to watch for: Nausea, vomiting, abdominal pain, irregular heart beat.

Food Interaction: None known at this time.

X. **LAXATIVE/STOOL SOFTENER**

What it does: Increase bowel movement, absorbs water and increases volume and bulk, lubricates.

What to watch for: Generally safe and without adverse effects. DO NOT take if abdominal pain, nausea, or vomiting is present.

Food Interaction: No saline laxatives for patients on sodium restricted diet. Not known at this time.

Y. **MUSCLE RELAXANTS**

What it does: Interferes with nerve impulses in muscle tissue.

What to watch for: Drowsiness, dizziness, upset stomach, confusion, changes in vision.

Food Interaction: No Alcohol

Z. **ANTIANXIETY AGENTS/SEDATIVES**

What it does: Reduces anxiety and tension, anti-seizure drug, promotes sleep, relieves muscle spasms.

What to watch for: Drowsiness, lethargy, dry mouth. DO NOT take with alcohol.

Food Interaction: Valium, Restoril, Ativan: Limit caffeine and No Alcohol.

AA. **ANTILIPIDEMICS**

What it does: Reduces serum cholesterol and decreases risk of heart attack.

What to watch for: Rash, constipation, or diarrhea, nausea, vomiting, blurred vision, headache, muscle ache and pains. Take with food to minimize stomach distress.

Food Interaction: Absorption of fat soluble vitamins (A,D,E,K) and iron may be impaired with long term use. Take vitamin supplement one hour before or 4-6 hours after drug. Grapefruit should not be taken at the same time with specific drugs.

BB. **VASODILATORS**

What it does: Dilates or opens blood vessels in the heart to increase oxygen to the heart muscle.

What to watch for: Lightheadedness, upset stomach, loss of appetite, constant dull headache. May cause swelling of feet. Take with food. Stand up slowly.

Food Interaction: None known at this time.

cc. **HORMONAL REPLACEMENT**

What it does: Replaces hormones necessary for normal body functions and regulation.
What to watch for: Consult MD if history of breast cancer or suspected pregnancy.
Food Interaction: None known at this time.

DD. **NARCOTIC ANALGESICS**

What it does: Central and peripheral action. Effective pain control. No action against inflammation.
What to watch for: Drowsiness, dizziness, nausea, vomiting, respiratory depression. DO NOT take with alcohol.
Food Interaction: None known at this time.

EE. **OPTHALMICS**

What it does: Eye medication containing various agents such as steroids, antibiotics, and lubricants. See specific classes for specific purpose.
What to watch for: Eye pain, cataract development (steroid containing), secondary infections.
Food Interaction: None known at this time.

FF. **ANTIGLAUCOMA AGENTS**

What it does: Relieves intraocular pressure by constricting the ciliary muscle, and various means.
What to watch for: Eye pain, irritation, tearing, visual blurring, retinal detachment, paradoxical increase in intraocular pressure.
Food Interaction: None known at this time.

GG. **VITAMINS/MINERALS/NUTRITIONAL SUPPLEMENTS**

What it does: Nutritional supplements for energy, metabolism, growth, and wound repair.
What to watch for: Generally safe. Take as directed.
Food Interaction: Recommend discussion with MD regarding potential interaction with prescribed medications.

HH. **HERBAL REMEDIES**

What it does: Nutritional supplements for energy, metabolism, hormonal balance, and growth.
What to watch for: Recommend discussion with MD regarding potential interaction with prescribed medications.
Food Interaction: Recommend discussion with MD regarding potential interaction with prescribed medications.

II. **BRONCHODILATORS**

What it does: Results in relaxation of smooth muscle of the bronchial airways and pulmonary blood vessels.
What to watch for: Nervousness, restlessness, headache, insomnia, muscle twitching, flushing, nausea, vomiting, and diarrhea. Take pills with milk or food to minimize stomach upset.
Food Interaction: Limit caffeine containing foods.

JJ. **NONSTEROIDAL ANTI-INFLAMMATORY DRUGS (NSAIDS)**

What it does: Produces anti-inflammatory, analgesic, and antipyretic effects.
What to watch for: Headache, dizziness, visual disturbances, nausea, abdominal pain, diarrhea, shortness of breath.
Food Interaction: Take with food. None known at this time.

THE FINAL JOURNEY

PREPARING YOURSELF

COMMON PHYSICAL SIGNS AND SYMPTOMS

COMMON SPIRITUAL/ EMOTIONAL/MENTAL SIGNS AND SYMPTOMS

As death approaches we do not need to turn away in fear. Instead we can choose to celebrate life and join hands with those we love. We can sing and dance and make merry in the face of the lengthening shadow. We can take the time that remains to add a few magical moments to our book of memories. And when the twilight falls and the moon rises and the one we love passes from us, we can take solace in the knowledge that we embraced and said good-bye.

~Author Unknown~

PREPARING FOR THE FINAL DAYS

Just as each person's life is unique, so too is his or her death. Because of this it is difficult to give hard facts about when the actual death will occur and what the actual death of the patient will be like when it happens. Therefore, some common concerns and approaches will be shared in this section.

When a person enters the final stages of the dying process, two different dynamics are at work, which are closely interrelated and interdependent. On the physical plane, the body begins the final process of shutting down which will end when all physical systems cease to function. Usually this is an orderly and peaceful progressive series of physical changes which are not medical emergencies requiring invasive interventions. These changes are a normal, natural way in which the body prepares itself to stop. The most appropriate kinds of responses to these changes are comfort-enhancing measures.

The other dynamics of the dying process are at work on the emotional, spiritual, and mental plane and it is a different kind of process. The spirit of the dying person begins the final process of release from the body, the immediate environment and all attachments. This release also tends to follow its own priorities, which include the resolution of whatever is unfinished of a practical nature. Reconciliation of close relationships and receiving permission to let go from family members are some of the events that take place at this point. These events are the normal, natural way in which the spirit prepares to move from this material realm of existence into the next dimension of life. The most appropriate kinds of responses to these changes are those which support and encourage the release and transition.

When a person's body is ready and wanting to stop, but the person is still unresolved or unreconciled over some important issue or with some significant relationship, he or she will tend to linger even though very uncomfortable or debilitated in order to finish whatever business needs to be finished. On the other hand, when a person is emotionally and spiritually ready for this release, but his or her body has not completed its final physical process, the person will continue to live until the physical body is ready to shut down.

The experience we call death occurs when the body completes the natural process of shutting down and the spirit completes the natural process of reconciliation. These two processes need to happen in a way appropriate for the values, beliefs and life style of the dying person so that death can occur as a peaceful release. Therefore, as you seek to prepare yourself as this event approaches, the members of your hospice team want you to know what to expect and how to respond in ways that will help your loved one accomplish this transition with support, understanding and ease. This is the great gift of love you have to offer your loved one as this moment approaches.

The physical, emotional, and spiritual signs and symptoms of impending death which follow are offered to help you understand the natural things which may happen and how you can respond appropriately. Not all these signs and symptoms will occur with every patient, nor will they occur in this particular order. Each person is unique and what has been most characteristic of the way your loved one has lived, will affect the way that he or she experiences dying. This is not the time to try to change your loved one, but the time to give full acceptance, support and comfort if you are able.

COMMON PHYSICAL SIGNS AND SYMPTOMS OF THE DYING PROCESS

1. Cooling of the body: The patient's hands, arms, feet and legs may become increasingly cool to the touch and the color of their skin may change or darken, which we refer to as mottling. This is a normal indication that the circulation is being shunted to the vital organs away from the extremities. You may do things to keep the patient warm (a blanket) but please do not use a heating pad or electric blanket on your loved one at this time. They will be unable to recognize if it is too hot and may receive a burn.

2. Sleeping: The patient most likely will spend more and more time sleeping, and appear withdrawn and uncommunicative. This too is a normal part of the dying process. Sit with your loved one and talk softly, or just hold his or her hand. Talk to him/her as you normally would, because he/she can hear you even if he/she cannot respond.
3. Confusion: The patient may seem confused about the time, place and identity of people surrounding them. Identify yourself by name and speak softly, clearly and truthfully when you need to communicate something important.
4. Incontinence: The patient may lose control of their bowel and bladder function as their muscles begin to relax. Your hospice nurse can provide adult diapers, bed pads or can place a catheter if necessary to help control skin breakdown which can result from excess moisture caused by incontinence.
5. Congestion: The patient may have noisy respirations. This is caused from pooling of secretions at the back of the throat and the patient is too weak to clear his own throat. This is not a painful or uncomfortable process, but is often hard for the family to listen to. Suctioning is typically not helpful in this situation and results in discomfort to the dying patient. Your hospice nurse can order a medication given in drops to help with congestion. Positioning the head of the bed in an elevated position or placing the patient on his side can help with the congestion.
6. Restlessness: The patient may begin picking at his clothing or the covers or carrying out repetitive motions. Speak in a calm, quiet voice to provide comfort.
7. Cessation of food and fluid intake: Usually the patient begins to want little food or fluids. This means the body is signaling that it cannot handle the food and fluid due to the imminent shut down. Encourage patients to take sips of water or bites of food, but DO NOT force. Forcing food and fluid for our own benefit often results in the patient vomiting making the patient much more uncomfortable. A cool, moist washcloth on the forehead may help; chips of ice or pieces of a frozen popsicle may be tolerated without causing adverse symptoms.
8. Hearing: Research indicates that the sense of hearing is the final sense to be lost. Therefore, speak in soft, calm tones and tell the patient what is on your heart and

mind. If there are difficult issues to be addressed with others, discuss those things out of the hearing of the patient to allow him peace.

9. <u>Urinary output</u>: The patient's output from their kidney's will decrease due to the decreased fluid intake, and also because the kidneys are no longer able to function.

10. <u>Breathing pattern changes</u>: The patient's regular characteristic breathing pattern may change with the onset of a different breathing pace which alternates with periods of no breathing. This is called "Cheyne Stokes respirations" and it is very common. Oxygen will neither help nor hurt at this point, but raising the head of the bed may make it easier on the patient.

COMMON EMOTIONAL, SPIRITUAL AND MENTAL SIGNS AND SYMPTOMS OF THE DYING PROCESS

1. <u>Withdrawal:</u> Your loved one may seem unresponsive, withdrawn or in a comatose-like state. This indicates preparation for beginning the process of letting go. Since hearing can remain with the patient all the way to the end, speak to your loved one in a normal tone of voice. Identify yourself when speaking, hold his hand and give permission for him to go, if you are able.

2. <u>Vision like experience:</u> The person may speak or claim to have spoken to persons who have already died, or to see places not presently accessible or visible to you. This does not necessarily indicate hallucinations or a drug reaction. The patient is beginning to detach from this life and is being prepared for the transition so it will not be frightening. Affirm their experiences and try not to deny what they are experiencing or try to convince them they have not seen what they have shared. Just because we cannot see or hear what they are describing, does not mean it is not real for your loved one. This is a very common manifestation of nearing death.

3. <u>Restlessness:</u> Patients may perform repetitive behaviors, such as picking at their clothes or blankets. This could indicate something still unresolved for them. Your

hospice team will assist you in identifying what may be helpful. Recalling pleasant memories, reading comforting literature, or playing music may help calm them. Medication may be helpful as well.

4. <u>Decreased socialization:</u> Patients may only want to be with few people, or even just one person. This is a sign of preparation for release. They are focusing their energy on this process and don't have energy to socialize also. It does not in any way mean you are unloved or unwanted. Affirm their ongoing value to you and recall the things you have learned from them. Simply being present with the patient at this time is often the most comforting intervention.
5. <u>Giving permission:</u> Being able to give permission to your loved one and telling him or her it is okay to go may be the single greatest gift which can be given. It is not easy, but the patient may need to hear that you will be okay and that those of you left behind will look out for each other. Then, when he/she no longer has to be concerned about how you will make it, he/she is able to relax and let go.
6. <u>Saying Goodbye:</u> This is your final gift of love to your loved one because it achieves closure and makes the final release possible. It may be helpful to lie on the bed with the patient to hold him/her in your arms, or to hold his/her hand and say the last goodbyes you need to express. This expression of love will also help you, so that later on you don't wish you had said what you were feeling, but didn't. You may need to say "I love you," "I forgive you," "Please forgive me," "Thank you for all you have meant to me," "I'll miss you, but I'll be okay." Tears are a natural part of saying goodbye and you do not need to hide your tears, nor apologize for them. Tears express your love, the hurt you are feeling, and help you to let go.

GRIEF

BEREAVEMENT

FINAL DETAILS

Continuing the Journey Together
The Bereavement Care Program of Reliance Hospice

The Bereavement Care program is a way for the staff of Reliance Hospice to continue the journey and ministry we have started together while caring for your loved one. Our concern for you and your family does not end when patient care is no longer necessary.

Grief is a very real part of life and a natural response to what you have experienced. People grieve in different ways, and all of these ways are valid. However, not all ways of grieving are healthy and healing. The Bereavement Care Program of Reliance Hospice has a singular goal – to help you grieve your loss in a healthy way which will allow some measure of healing to take place in your life. It is not our purpose to make you "forget" or move forward more quickly than you are able to. No one ever forgets, however, hopefully we can help you find a manner of remembering which is not as painful as it is now. Also, everyone moves at a different pace through this journey into the rest of life. You will set your pace. You will determine how active we are in that process of grief and healing for you. This is *your* grief process related to *your* experience of loss. We do not want to rob you of your right to grieve. We simply hope to help.

As a part of the Bereavement Program, your needs, and your family's needs, will be evaluated by the people who have been a part of your caring team through Reliance Hospice. Also, one of our bereavement counselors will contact you for a personal visit to help you evaluate and express your needs. For at least the next thirteen months, if you so desire, members of our staff will be in touch with you. You will receive mailings which are specifically designed for people going through grief and recovery. There will be cards sent from time to time on special days to let you know that we are with you. Though members of our staff are no longer giving patient care to a member of your family, *you matter to us!* We are still here to help in any way we can. As we often remind families, "The same phone number still works. If you need us, please call."

Some people will look at what you are experiencing and call it an "end". We prefer to call it a "step". The journey goes on and we are here so that you do not have to make these first steps toward tomorrow alone.

Your friends and companions at Reliance Hospice

Some Information You May Find Helpful

Grief: A Definition

Grief is a natural and normal reaction of any kind. It is a journey of experiences and feelings in response to that loss, and a process of adjustment because of that loss. Grief is not an option, but a necessary mechanism for health and well-being.

We feel grief all over. It is physical, emotional, spiritual, psychological, and social. Grief is a very personal journey. The deeper the feelings towards the person and relationship we have lost, the deeper the need to grieve. Grief hurts because of the love which drives it.

Grief is a journey which is never fully completed. We do not “get over” our loss. Hopefully, we recover enough to begin to move forward in life. Grief and recovery are based on many factors: lifestyle, personal history, past experiences of loss, and family network. Grief also involves many feelings such as anger, love, bitterness, regret, relief, doubt, and sometimes guilt. Grief can include depression, physical and behavioral changes, and variances in interests and lifestyle.

Grief is a process of serious actions, reactions, and the makings of new pathways to travel while honoring the journey we have taken to this time. It affects our attitudes and feelings about ourselves, our situation, those around us, and the one we have lost. The process of grieving is not a straight line to an expected goal, but a series of steps forward, sideways, backwards, and upside down. There is not a timetable. Be very gentle with yourself and others. *And <u>never hesitate to ask for help</u>.*

Some Thoughts on Grief and Mourning

Grief is not very well understood in our society, and mourners are expected to recover quickly. The experience of grief is unique to each person even though there are many similar experiences of loss. Guard against putting your expectations on others – and against accepting the expectations of others as your own.

Tears make many people uncomfortable but they are a healthy and acceptable part of the pain process. Cry when you need to and do not feel the need to apologize.

Grief affects the total person. A balanced diet, adequate fluids, exercise, and rest are important during the mourning process. You may not realize immediately the amount of energy you have expended over the last weeks and days. It is not unusual to feel exhausted. It is always wise to see your personal physician within a few weeks for a general checkup.

Friends and relatives may avoid talking about the death of your loved one. Let them know if you need to talk about your loved one and if talking helps. Your feelings and emotions are real. Find people who will let you express those feelings honestly and openly without judgment.

This is a very difficult time of transition for you. If possible, avoid making major decisions for a few months. When necessary decisions have to be made, try to secure sound advice which you trust.

There will be a certain group of people who encourage you to move your loved one's clothes and possessions immediately out of the house. Wait until you are ready to decide what to do.

Holiday and anniversary times are reminders of your loss. As much as possible, try to plan ahead in order to avoid the added stress at those times. Remember that others may not understand or be sensitive to your feelings. Take time for your needs.

You are not alone. Mutual help groups can put you in touch with others having a similar experience. There are people who understand and who care, let them help.

Grief: What Do I Need?

TIME	Allow yourself the time necessary to deal honestly and fully with what is happening to you.
REST	Relaxation, exercise, nourishment: you may need extra amounts of the things you have always needed. You need to replenish yourself or give yourself a lift. Follow what seems healing to you and what connects you to people who care.
SECURITY	Find your routine. Find people whom you can trust to help you with matters you may not understand or which cause you stress.
CARE	Even though it may cause you to feel a bit uncomfortable, and the persons offering care may be uneasy and awkward, allow yourself to accept their efforts.
GOALS	For a bit, it may seem that much of life is without meaning or direction. At such times, small goals are very important. Live one day at a time and set small, measurable, realistic goals for your day and week.
GIFTS	Do not underestimate the healing effects of small pleasures and gifts. Watching a sunset, a walk, a favorite food, a massage, a warm tub, an afternoon nap – give yourself small gifts which make your day better.
PERMISSION	**This may be the most important of all. Give yourself permission to make this journey. Give yourself permission to do what you need to do. Give yourself permission to be the center of your attention for a bit. Give yourself permission to backslide sometimes. Give yourself permission to take your time. Give yourself permission to say what you need and do not need from others. Give yourself permission to trust.**

NORMAL AND HEALTHY RESPONSES TO GRIEF

Immediately following a death, there is a sense of shock, numbness, and disbelief that can last minutes or weeks. The person may feel panicked or overwhelmed and experience strong physical reactions. When there has been a lengthy illness, the griever may experience a sense of relief for the person who died and for themselves now that the stresses of care giving are over. This period allows the person to take information in at a slower rate and to prepare for the adjustments that lie ahead. Most people who suffer a loss experience one or more of the following:

Social

- Withdrawal from others
- Dependence on others
- Fear of being alone

Physical

- Palpitations
- Shortness of breath, crying
- Diarrhea, constipation, vomiting
- Tightness in the chest or throat
- Change in appetite or sleep patterns
- Lack of energy; fatigue

Emotional

- Sadness
- Numb, empty, flat expression
- Guilt and self-reproach
- Anger and/or anxiety
- Indifference to daily activities

Cognitive

- Confusion, sense of unreality
- Poor concentration, forgetfulness
- Denial, disbelief
- Constant thoughts about the person
- Dreams of the deceased

Spiritual

- Blaming God
- Lack of meaning or direction
- Loss of faith
- Wanting to die/join the dead person

COMMON *GRIEF EXPRESSIONS*

* "Why is this happening to me? What did I do to deserve this?"

* "If only I had told him/her one more time, I love you."

* "I think I'm losing my mind; I can't concentrate on anything."

* "The nights and weekends are the worst for me – empty and lonely."

* "If my faith were stronger, I would be able to handle this."

* "I have trouble getting to sleep and, after I finally do, I only sleep a few hours before I'm up again."

* "It's as if any time now, he'll call or walk through the door. I keep thinking of things to tell him."

* "I hate you! Get out of here! Leave me alone."

GRIEF-EXPECTATIONS YOU CAN HAVE FOR YOURSELF

You can expect that:

Your grief will take longer than most people think it should.

Your grief will take more energy than you can imagine.

Your grief will involve continual changes.

Your grief will show itself in all spheres of your life and who you are. It will affect your social relationships, your health, thoughts, feelings and spiritual beliefs.

Your grief will depend upon how you perceive the loss.

You will grieve for many things (both symbolic and tangible), not just the death itself.

You will grieve for what you have lost already, as well as for the future – for the hopes, dreams and unfulfilled expectations you held for and with that person.

Your grief will involve a wide variety of feelings and reactions; some expected, some not.

This loss will resurrect old losses, feelings, and unfinished business from the past.

You may have some confusion about who you are; this is due to the intensity and unfamiliarity of the grieving experience and uncertainty about your new role in the world.

You may have a combination of anger and depression: irritability, frustration, intolerance.

You may feel guilt in some form.

You may have a poor sense of self-worth.

You may experience spasms, waves, or acute upsurges of grief that occur without warning.

You will have trouble thinking and making decisions.

You may have poor memory and organization.

You may feel like you are going crazy.

You may be obsessed with the death, or preoccupied with thoughts of the dead person.

You will search for meaning in your life and question your beliefs.

You may find yourself acting differently.

Society has unrealistic expectations about your mourning and may respond inappropriately.

You will have a number of physical reactions.

Certain experiences later in life may resurrect intense grief feelings for you.

The Four Tasks of Mourning

The first task is to accept the reality of the loss:

A) This means acknowledging that the loss has occurred
- that the person is dead and will never return
- such acceptance is never easy
- something inside tries to prove it is not true

B) Thus, efforts to accomplish this task often meet with resistance
- one is denying the facts
- another is denying the meaning
- still another is denying that the death is irreversible

Conclusion: the task of acceptance is accomplished as the griever lets go of normal and healthy forms of denial and faces fully the facts, meaning and irreversibility of what has happened.

The second task is to experience the pain of grief:

A) Significant loss always causes pain
- it hurts to lose someone or thing that was dear
- it is important to acknowledge and work through this pain
- at the same time, society, family and friends may be uncomfortable with our pain
- society's reluctance to let us hurt may blend with our desire to avoid pain

B) People often seek to avoid the pain of grief by trying "not to feel"
- they attempt to avoid feeling in a number of ways
- all these attempts to avoid feeling will ultimately backfire

C) What can you do to work on this task?
- allow yourself to feel the whole gamut of emotions that loss may arouse
- give yourself permission to express your feelings
- talk about your missing loved one and the circumstances of the loss

The third task is to adjust to an environment in which the deceased is missing:

A) This adjustment means different things for different people
- it means the realization of what it's like to live without the deceased
- survivors at times resent having to assume some of the roles of the deceased
- in assuming new roles, the survivors learn new skills, thus increasing their self esteem

B) People often try to resist change by simply not adjusting
  - some promote their own helplessness
  - some refuse to develop the new skills they need
  - others may withdraw from the world and not face up to the new circumstances

C) How does one go about the process of adjusting?
  - acknowledge that things are going to be different
  - sort out what has to be done “right away” from that which can “wait awhile”
  - being to take steps to learn new skills needed to survive and eventually thrive

<u>The fourth task is to withdraw emotional energy from the deceased and reinvest it in others:</u>

A) This is often the most difficult of the four tasks to accomplish.
  - some misunderstand the purpose – feeling that withdrawing energy is a betrayal of the deceased
  - others are afraid to reinvest emotions for fear this too will result in loss
  - others cling to the notion that they are married for life
  - some encounter the disapproval of children and friends

B) The completion of task four is essential to a healthy grief cycle
  - failure to withdraw is characterized by a diminished capacity to love
  - failure to reinvest stops the grief cycle short of completion
  - this failure is not necessary as reinvestment does not mean betrayal

C) How do we accomplish this task of withdrawal and reinvestment?
  - let it happen naturally
  - let yourself be drawn back into both old and new activities
  - let yourself become interested again in other people

To Heal, It Is Important To:

1. Do not condemn yourself. “If only” will only slow the process down.
2. Don’t drug yourself – it is easy for others to try to ease our pain by giving pills which only leave a dull pain for a longer time.
3. Take one day at a time.
4. Set limits and be realistic.
5. Don’t cross bridges until you come to them – it is best to not make any major decisions when off balance.
6. Don’t withdraw – you need others.
7. Attend to other people’s intentions – not their words.
8. Don’t run away – the best place to adjust is at home.
9. Let yourself feel. Stop saying “I should feel better already.”