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- List of available agencies within your community
- Quality measures from reported outcome data

This information can be used as a measurement tool for clients and families to determine the quality of services provided by an agency. It can also be used to compare the care delivery of one agency to another, in order to determine what agency might better serve their health care needs.

CHCS outcome scores can be viewed at www.medicare.gov/HHCompare.

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Guidelines For End of Life Care



CHCS's Home Health and Hospice Coming Home to Caring

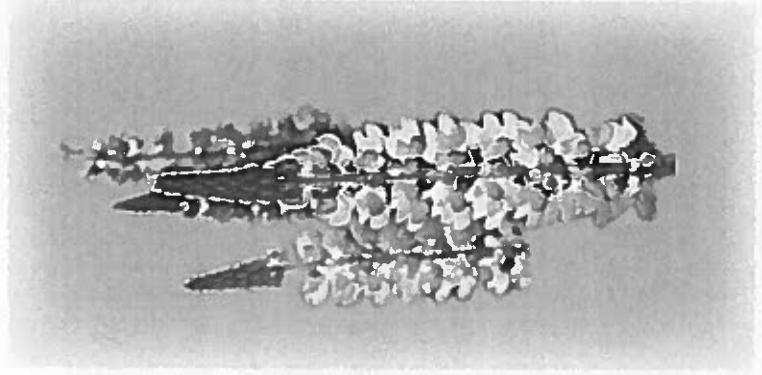


Compliments of

Community Health and Counseling Services

GUIDELINES FOR END OF LIFE

What follows is a description of the physical and emotional changes that you may expect at the end of life. You and the patient may experience all or only some of them. This guideline offers you practical responses that hopefully will make this easier for you and the patient. Remember, there can be happy times as well as hard times. Your support is the greatest gift you can offer the patient at this time. Your nurse and your doctor will be available for further advice and support.



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PHYSICAL CHANGES

EATING/DIGESTION

1. Decreased appetite, decreased thirst.

This is natural as the body begins to slow down. You may try to maintain the patient's weight as long as this is reasonable, but when the patient no longer wants to eat, don't force him/her.

Ways to help:

- Offer patient ice chips or small sips of cool liquid.
- Provide small frequent meals of food the patient likes.
- Keep desired snacks in easy reach of patient.
- Use prepared high-calorie supplements such as instant breakfast, Ensure, Sustacal (alone or with meals).
- Increase calories in food by adding powdered milk, butter, margarine, protein supplement, mayonnaise, cooked eggs, honey, peanut butter (just the opposite of what you do to lose weight).

2. Thirst, dehydration, trouble with swallowing.

Dehydration and thirst are often caused by trouble with swallowing or diarrhea. Providing enough liquid to the patient will make him/her more comfortable.

Ways to help:

- Offer liquids frequently; patient may be too weak to ask.
- A straw may be easier for patient than sipping.
- A damp washcloth on lips may aid comfort.
- Stimulate saliva with hard candies or mints if patient can swallow.
- For swallowing problems, have patient sit as upright as possible so patient won't choke.
- Soft foods (custards, puddings, cream sauces, pureed food) are easier to swallow than solids. If using a blender, heat food first, then blend.
- Food can be softened by dipping in coffee, tea, milk, broth, gravy.

- Provide mouth care: Keep mouth moist and clean of old food. Use soft toothbrush or sponge toothbrush. Protect lips with Vaseline or other lip balm. Remove dentures except for eating if they are irritating patient.

3. Nausea/vomiting.

This can be the side effects of the illness, constipation, medications, or anxiety. Where possible, eliminate the source of the problem with help from your nurse or doctor. If patient can't keep any fluid down, notify the doctor.

Ways to help:

- Have patient eat dry crackers before getting up in the morning.
- Provide ginger ale, popsicles, ice chips or "water popsicles" for patient to sip slowly. Allow carbonated fluids to go flat.
- Serve small meals every 2-3 hours; have patient eat slowly and rest after meals.
- Have patient take slow deep breaths before eating.
- Food at room temperature is best; avoid very hot or very cold foods
- Provide frequent mouth care.
- Keep room aired of unpleasant odors
- Avoid sweet or spicy or greasy foods.
- Check with nurse for nausea medication.

4. Hiccups.

This can be the result of the illness or medications

Ways to help:

- Have patient re-breathe in a paper bag not more than 10 times.
- Have patient hold breath as long as he/she can.
- Try peanut butter.
- Add sugar or peppermint to water.
- If hiccups last for more than one day, notify nurse because patient may need medication.

5. Constipation.

This often is caused by pain medications, illness, or the decrease in food and exercise. Prevention of constipation is the goal. Almost all patients taking narcotic medications such as morphine (MS Contin, MSIR) and Oxycodone (Percodet, Vicodin) must take a laxative/stool softener (Senokot-S) everyday.

Ways to help:

- Encourage liquids as tolerated.
- Add 1-2 TBS bran to foods if tolerated.
- Ask the nurse about a stool softener and laxative.
- Daily prunes or prune juice (warm works even better).
- High fiber foods as tolerated such as raisins, granola, fruits, vegetables, whole wheat and bran as tolerated.
- Encourage physical activity as much as patient can tolerate.
- Allow plenty of time and privacy for bowel movements.
- Use a sitting position if patient is using a bedpan.
- Avoid constipating foods such as cheese, rich desserts and chocolate.

6. Diarrhea/Gas/Cramps.

Diarrhea can be caused by radiation therapy, chemotherapy, anxiety, medications, or the illness.

Ways to help:

- Provide clear liquids (any liquid you can see through) between meals, not with them. Examples are broth, clear juice, Gatorade, Kool-Aid, Jello.
- Provide cooked fruits and vegetables. Avoid those with skins and seeds.
- Allow carbonated beverages to go flat before drinking.
- Avoid spices, gum, dairy products, and gassy foods such as beans, onions, cabbage, broccoli, cucumber, peas, corn, spinach, radishes, nuts, caffeine.
- Avoid high-fat and high-fiber foods (see list under Constipation).
- Try crackers, pasta, cream of wheat, oatmeal, rice, tapioca, peanut butter.
- Add nutmeg to foods.

- Keep rectal area clean, dry and use barrier lotion such as lanolin or Vaseline.
- Talk to nurse about medications.

BREATHING

1. Chest congestion with or without cough.

This can be caused by the illness and/or if the patient can't cough up mucus.

Ways to help:

- Provide enough liquid intake to keep mucus loose.
- Provide humidity in room air. Use a humidifier, nebulizer, or open pan of water on stove or radiator.
- Assist patient to position that is easiest for him/her to cough up mucus (usually sitting up).
- Avoid milk/milk products (they may increase mucus production).
- If cough becomes unbearable -- contact nurse.

2. Breathing pattern changes.

This is a normal part of the body's slowing. It can also be a direct effect of the illness or medication. The rate may increase or decrease, and there may be long pauses without breathing.

Ways to help:

- Remain calm with patient. Anxiety may cause a patient to have difficulty breathing.
- Elevate head or upper body.
- Turn person onto side or position of greatest comfort for breathing.
- Provide fresh air; sometimes a fan helps with "air hunger".
- Use oxygen if you have it - ask nurse if this is an option for you.
- Ask the nurse about use of morphine to relieve symptoms.

WEAKNESS, FATIGUE, LOSS OF ENERGY

This is natural as an illness progresses. Certain things make patients more at risk for this such as: depression, fever, and medications.

Ways to help:

- ☒ Schedule activities so the the patient does what he/she likes to at a time when he/she has the most energy.
- ☒ Set aside time for frequent naps.
- ☒ Assist the patient with bathing and feeding if needed.
- ☒ Keep commode or bedpan by bedside if getting up to the bathroom tires patient.
- ☒ Eliminate low-priority activities if it makes patient tired, e.g. daily bath.
- ☒ Place items that the patient uses frequently near his/her bed.

TEMPERATURE AND CIRCULATION: SKIN CHANGES

As the body systems slow, there is less circulation. The patient may be cool, especially in hands and feet. He/she may alternate between feeling cold and hot with increased sweating.

Ways to help:

- ▲ Keep patient warm with blankets but not electric blankets or heating pad (there is a risk of burns). Warm blanket in the dryer.
- ▲ If patient "can't get warm", get in bed with patient and hold and comfort him/her.
- ▲ When patient is sweating, keep him/her as clean and as dry as possible to prevent chilling.
- ▲ If patient spends long times in bed or a chair, help with position changes every two hours.
- ▲ Lightly massage bony areas that take the pressure of the patient's body - ankles, knees, hips, back, shoulders, elbows.
- ▲ Keep bedding clean, dry, wrinkle-free.
- ▲ If patient has a new fever above 101, call your nurse.

BLEEDING

This may not be a problem you should expect. Talk with your doctor or nurse. If bleeding is a likely possibility, talk with your nurse for a plan to manage this.

Ways to help:

- ☒ Remain calm.
- ☒ Be prepared with Chux or dark towels to absorb blood
- ☒ Know what your back-up plan will be if this becomes too hard to deal with.

PAIN

Pain is the most feared symptom at end of life. It is also a very individual matter. Only the patient knows how much pain he/she is having and how well the remedies are helping.

Chronic Pain (long-term, non-ending) needs regular medication (on a schedule). Letting chronic pain go until it becomes unbearable makes it difficult to relieve.

Acute Pain (short-term pain like a headache) responds to pain medication "as needed". You and the patient need to discuss with your doctor and your nurse the types of pain the patient is experiencing. There are medications to take care of most pain but often you must try a few to find which works the best.

Only the doctor can prescribe pain medication; therefore you must have good communication with him/her.

Common mistakes regarding pain and pain medication:

- ☒ Patient believes the pain is inevitable and untreatable.
- ☒ Patient doesn't communicate about the pain to the doctor.
- ☒ Patient puts on "brave front" for family or doctor and doesn't reveal how much pain.
- ☒ Patient fails to take medication as scheduled or at all. "Doesn't believe in drugs".

- Belief by patient or caregiver that pain medication should not be given "unless absolutely necessary". Thus chronic pain gets out of control.
- Patient or caregiver fears addiction. A patient in chronic pain does not become addicted.
- Belief that a tolerance will develop and then there will be nothing for when the pain gets "really bad". There are many pain medications. When one fails, there is another or a combination.
- Patient stops medication because of side effects or another reason and doesn't ask doctor for a replacement.

Ways to help:

- Talk often with patient and nurse about the type of pain involved and what level of relief is desired.
- Ease emotional pain with enjoyed activities, such as visitors, listening, massage, music, etc. With less emotional pain, physical pain may be less.
- If you are giving pain medication, make sure you follow prescribed schedule. Ask the patient often how well his/her pain is controlled. Try alternative pain control measures such as imagery, visualization, medication, therapeutic touch. (Ask your nurse about these.)

SEIZURES

Discuss with your doctor how likely an event this will be. A seizure can be 2-5 minutes of jerking muscles with periods of limpness. The patient may be confused and/or sleepy for several hours afterwards.

Ways to help:

- Loosen patient's clothing.
- Turn patient on side so fluids can drain from mouth.
- Protect patient from sharp objects, falling off bed, or hurting self in any other way, but do not restrain. Stay with patient.
- If seizure continues more than 5 minutes, or is new event, call your nurse.

- Medications are available to prevent seizures. Talk with your nurse if this is a concern.

MENTAL, SPIRITUAL AND EMOTIONAL ASPECTS

The other part of the dying process is the emotional-spiritual-mental part. The patient may express a desire to have clergy available at this time. The patient may seek permission to "let go" from family members. These "events" are the normal natural way in which the patient's spirit prepares to move on. The best response is to support and encourage the patient.

The following signs and symptoms of approaching death are offered to help you understand the natural kinds of things that may happen and how you can respond.

1. Unresolved conflicts.

When a person's body is ready and wanting to stop, but there is still an unresolved issue or relationship, he/she may tend to linger in order to finish whatever needs finishing. Your understanding and support will help the patient.

2. Withdrawal.

A person begins to withdraw from the world around him/her. This is the beginning of separation, first from the world - television, newspaper; then from people - neighbors, friends; and finally perhaps from those most loved. The person may sleep more, seem unresponsive, or may seem to be in a coma-like state. This is a beginning of "letting go". Since hearing remains till the end, speak to the patient in a normal tone of voice, say your name when you speak, hold his/her hand, and say what you need to say to help the person "let go".

3. Vision-like experiences.

The patient will often become confused, talking to people and

about places that are unseen to others. They may see and talk with loved ones who have died before them.

Do not contradict, explain away, or argue about what the person claims to have seen or heard. It is very real to the patient. Affirm his/her experiences; they are common and normal.

4. Restlessness.

The patient may become agitated or lose sense of present reality or he/she may pick at the bedclothes, try to climb out of bed, or be fidgety.

It may help to show him/her familiar objects. Keep photographs nearby, put a calendar or large clock with a lighted face near him/her, gently and repeatedly identify the time and day, read something comforting or play favorite music. If it gets worse, your nurse should be contacted.

5. Confusion.

The patient may seem to be confused about the time, place, and people surrounding him/her, including close and familiar people.

Say your name when you speak. Speak softly, clearly, and truthfully when you need to communicate something important for the person's comfort such as, "It's time to take your medication now so you won't begin to hurt."

6. Giving permission.

A dying person will usually try to hold on in order to be sure that those who are going to be left behind will be all right. One of the greatest gifts you have to give the patient at this time is to let him/her know it is all right to let go whenever he/she is ready.

SIGNS OF APPROACHING DEATH

This is a very general time frame of the expected signs of dying. Remember: It may be like this in your situation; it may be very different. If you have any questions about what is happening, talk with your nurse or doctor.

Final One to Three Months.

- Withdrawal from the world and people (including family)
- Less communication
- Eating less
- Sleeping more

Final One to Two Weeks.

- Agitation
- Talking with unseen people
- Confusion
- Picking at clothes
- Decreased blood pressure
- Pulse (heartbeat) increase or decrease
- Skin color changes: pale or bluish or yellowish
- Increased sweating
- Breathing changes
- Chest congestion
- Sleeping but responding to voice or touch
- Complaints of body tired and heavy
- Not eating, taking little liquid
- Body temperature, hot or cold

Final Days or Hours

- Surge of energy
- Decrease in blood pressure
- Eyes glassy, watery, half open
- Unusual breathing, long pauses
- Restlessness or no activity
- Blotchy purplish knees, feet, hands
- Pulse (heartbeat) weak and hard to feel
- Less urine
- May wet or stool the bed

Final Minutes

- Difficulty breathing
- Cannot be awakened



THE FINAL DAYS OR HOURS BEFORE DEATH

1. General agitation.

Patient may show restlessness, need for fresh air, thirst, possible sweating, and may not want to lie on back.

Ways to help:

- Sponge/ massage patient's body.
- Offer ice chips or sips of water if patient is able to swallow.
- Use salve on lips if dry.
- Medications may be needed for agitation.
- Assist patient with position of comfort.

2. Temperature and Circulation.

The patient's heartbeat slows, becomes irregular, and pulses are hard to feel, which all mean the circulation is slowing. The hands/feet may be cold and bluish. Face color may be gray with bluish lips.

Ways to help:

- Adjust blankets to keep patient feeling comfortable. Use as few as possible; the weight of blankets may feel confining.

3. Digestion.

The muscles that aid digestion slow down. Eating and bowel movements may slow down or stop.

Ways to help:

- Offer sips, ice chips, as long as patient can swallow.
- Provide good mouth care when patient can no longer swallow.

4. Breathing.

Breathing may become very fast and then become irregular and shallow with long pauses. Then they will gradually slow to zero. Mucus may collect in the throat and "gurgle". This is generally more disturbing to the caregiver than to the patient.

Ways to help:

- Assist patient in whatever position helps with breathing.
- Provide good support for comfort (may be on side with head up or propped up sitting).
- Use oxygen if ordered.
- Turn patient to side to drain mucus if it is collecting.

5. Decreased awareness.

The patient may sleep more. He/she may be alert or may be disoriented, and speech may become unclear. Senses begin to dull with hearing being the last to go.

Ways to help:

- Talk and touch even if patient doesn't respond.
- Don't talk about patient as if he/ she weren't there!

6. Eyes.

The eyes may be sunken or glazed with pupils enlarged. They may be watery.

Ways to help:

- Keep eyes cleaned.
- Provide damp cloth if it eases eye discomfort .

7. Pain.

The patient may not be able to communicate about pain. If this is the case, watch for restlessness, moving around in the bed, anxious sounds, or facial expressions such as grimaces, wincing or flinching. Continue your pain measures and notify nurse if they don't work.

8. Saying Goodbye.

When the person is ready to die and you are able to let go, then is the time to say goodbye.

There are many ways of saying goodbye. It may be helpful to lie in bed with the person and hold him/her or to take their hand and say what you need to say. It may be as simple as, "I love you." It may include recounting favorite memories, places and

activities you shared. It may include, "I'm sorry for _____" and it may also include "Thank you for _____".

Tears are a normal and natural part of saying "goodbye". They do not need to be hidden or apologized for. Tears express your love and help you to let go.

WHEN DEATH OCCURS

Signs:

- NO breathing, NO heartbeat (pulse).
- Release of bowel and bladder.
- No response to anything.
- Eyelids slightly open.
- Pupils enlarged.
- Eyes fixed on a certain spot.
- No blinking.
- Jaw relaxed, mouth slightly open.

This is not an emergency. You have met your goal of the patient dying at home and the patient has left this world surrounded by your support and care.

There is no "right" way to react. Do what you need to do to say goodbye and grieve. This is the time for you and your needs. The body does not need to be removed until you are ready. A nurse can be with you at this time if you wish.

Notify:

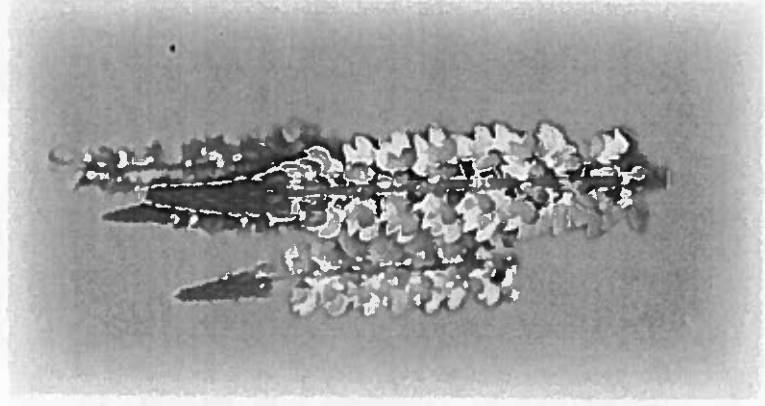
- The doctor.
- The funeral home; the funeral home staff will come to take the patient's body when you call.
- Other family members; have list of names and numbers near phone.

GRIEVING

Grief is a normal, natural process that occurs because of a loss. Each person grieves differently. Some emotions that are part of grieving include denial of the loss, anger at self or others, guilt and deep sadness. Some physical complaints that are part of grieving are tiredness, loss of appetite, difficulty sleeping and excessive crying.

Each person's grief lasts a different length of time. You may start to feel better and then sad feelings return on anniversaries, birthdays and other special occasions. This is natural and okay.

If your grief lasts a very long time or you feel helpless or hopeless, please talk to a clergy person or counselor.



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Prepared by:
Margaret Buschmann RN
Beverly Duplessis RN
Cathi Goebel RN

