WHAT TO EXPECT AT END OF LIFE

FOOD AND FLUIDS AT THE END OF LIFE

Just as there is a natural yet miraculous process for birth, there is also a natural process in death. One of the differences between these two processes is while birth is widely celebrated the details of dying are rarely discussed. Hospice is founded on the belief that the body adapts as a disease progresses and death approaches, and this process should not be interfered with unless it benefits the patient.

During times of great distress, families turn to familiar traditions for providing comfort and expressing love. Food is one of those rituals, providing nourishment for the body and soul and part of a family’s language of love and comfort. When your loved one stops eating and drinking, it is normal to feel helpless because food and water is considered to be a requirement for good care and love. It is important to understand that good care can be expressed in ways other than eating and drinking. For the majority of patients with advanced disease process, food and fluids do not increase the quality or quantity of life. In fact, when a person is artificially fed and/or hydrated, it can actually increase his or her pain and suffering. Allowing your loved one to accept or refuse food and fluids enhances his or her control and the quality of life.

Experience and evidence show that death without artificial nutrition and hydration is a natural process. The body is an amazing machine, even at the end of life. Most dying patients feel little hunger. They eat and drink very little or refuse all food and fluids. As a family member, remind yourself that this is not a healthy person refusing to eat and experiencing hunger pains. Adding food and fluids at this time may cause your loved one unnecessary stress.

As disease progresses and death approaches, organs decrease their normal level of functioning. When a person is fed at this point, the body is unable to process food and fluids normally. The outcome may cause discomfort and increased suffering, resulting in symptoms such as swelling, bloating, choking, coughing, nausea, vomiting or difficulty breathing. Please keep in mind that feeding through a tube or IV is the same as giving food and fluids.

Dehydration is a natural anesthetic. In the dying patient, dehydration provides relief through a change in mental status that can lessen the patient’s awareness of suffering. Not eating should be looked on as one of the components of the natural dying process and not the cause. The most negative side effects of dehydration include thirst and dry mouth, which can be alleviated with good mouth care. Mouth care provides an opportunity for you to express your care and love in a new way. The Tidewell team will
teach you about providing good mouth care that can bring relief to your loved one and allow you quality time together. Always remember to let your loved one be the guide to what he or she needs or desires.

**AS THE TIME OF DEATH NEARS**

Tidewell Hospice realizes that in the final stage of your loved one’s terminal illness, your anxiety of the unknown brings many questions to mind. This section is designed to assist you with recognizing signs that appear in most people as the body systems slow down and finally stop functioning, what members of the Tidewell team may refer to as transitioning. This section also offers suggestions as to how you can support your loved one during this time.

First be aware that the death process is very individualized; for some, these signs begin to appear a few hours before death, while for others they may appear a few days or weeks before. These events occur in no particular order and may not occur at all. By knowing what to expect, Tidewell hopes that you may be more comfortable as you and your loved one experience this time together. You know your loved one better than anyone and can respond best to his or her personal comfort needs. Sometimes this may be as simple as sitting or lying with your loved one and giving the comforting assurance that you are there. Tidewell is there to assist as you develop ways that can help your loved one accomplish this transition with support, understanding and ease. This is the greatest gift of love you have to offer during this time.

When a person enters the final stage of their life, two different things are happening. On the physical side, the body begins the final process of slowing and shutting down. Physical changes are a normal part of this process, though they vary from person to person and are impacted by specific disease processes.

On the emotional/spiritual side, a dying person often begins to let go of their environment and relationships. It is a natural way in which many people begin to transition. Your support, understanding and encouragement is very helpful during this time. If you feel your loved one is having a difficult time emotionally or spiritually during this transition, you may want to seek support and more specific guidance from your Tidewell team.

Not all of the signs and symptoms presented here will occur with every person. These pages serve as a simple guide to assist you as you care for your loved one. Again, it is important to remember that the dying process is as unique as life itself. Each person needs to do things in his or her own way. This is not the time to change lifelong habits or dictate an approach to death, but a time to give your full acceptance, support, and comfort.
Among the dying there is a shift from a mental processing of death to a true comprehension and belief in one's own mortality. Unfortunately, this understanding and the work of processing it may not always be shared by others so be open to your loved one's expression of it.

If the following signs and symptom were to be put on a flexible timetable, it could be said these changes begin one to three months before death occurs. The actual dying process, how the body prepares itself for the final stage of life, often begins in the two weeks prior to death.

As these last days pass, loved ones and friends often ask what they need to do during this time. Besides keeping the patient clean and comfortable, some families sit by the bedside to share stories, read aloud, sing special songs or play favorite music. Even if the patient does not seem to hear or recognize the people around him or her, it is often thought that he or she hears what is being said.

Touch is also important. You have the best personal knowledge of what your loved one might find comforting. For some, gently rubbing lotion on the back, arms and legs can be soothing. Sometimes it is enough to just hold hands so your loved one knows he or she is not alone. There are no rules: family and friends usually do just the right thing by doing what comes naturally. Special memories can be made and shared during this time.

**ONE TO THREE MONTHS PRIOR TO DEATH**

**Fluid and food decrease:** Food is fuel for the body. It is the means by which people keep their bodies going, moving, alive. We eat to live. When a body is preparing to die, it is perfectly natural that eating should stop. This is one of the hardest concepts for a family to accept. Your loved one may have a decrease in appetite and thirst, wanting little or no food or fluid. The body naturally begins to conserve the energy which is used for these tasks. Do not try to force food or drink or try to trick your loved one into eating or drinking something he or she does not want. There is a gradual decrease in eating habits. Nothing tastes good. Cravings come and go. Liquids are preferred to solids. You may hear him or her say: “I just don’t feel like eating.”

Meats are the first to go, followed by vegetables and other hard to digest foods until even soft foods are no longer eaten. Normal hydration is often not possible. We have found that the dying process is more peaceful in a state of dehydration than a state of fluid overload. Small chips of ice, frozen juices and Popsicles® may be refreshing in the mouth. Be careful of problems with swallowing and do not force fluids if the person coughs soon after swallowing. The person’s body lets him or her know when it no longer desires or can tolerate food or liquids. Dehydration does not make the patient uncomfortable.
The Tidewell nurse may suggest mouth swabs and frequent mouth care to provide moisture to the mouth. At this point, it is okay not to take food or fluids.

**Decreased socialization/withdrawal:** It is not uncommon for your loved one to experience a period of withdrawal or separation. As he or she processes the impact of “yes, I am dying,” a person begins to withdraw from the world. This may signal the beginning of the emotional pulling away from environment. He or she may begin to show no interest in newspapers or television; this may include no desire for visits from neighbors or friends. There may even be a feeling that the person does not wish to be a burden to others and excluding the people he or she loves the most.

With this withdrawal may come less of a need to communicate with others. The person may want to be alone, with just one other person or with a very few close people. It is natural to not feel like socializing when weak and tired. Reassure your loved one it is okay to sleep and rest. Honor the need for quiet time, calming and intimate surroundings.

You may wish to sit with your loved one and hold his or her hand. Speak directly, softly and naturally, as you normally would. Even though there may be no response, never assume your loved one cannot hear you. Hearing is said to be the last of the senses to be lost. Make sure the words spoken around your loved one’s bedside are calming and reassuring.

**Sleeping:** The person may spend an increasing amount of time sleeping. A morning nap is added to the usual afternoon nap and he or she may appear to be sleeping all the time and difficult to arouse. This is a normal change due in part to changes in the functioning of the body. You may wish to sit with your loved one, holding his or her hand, and speaking softly and naturally. Plan to spend time together when he or she is most alert. At this point, “being with” is more important than “doing for.”

**ONE TO THREE WEEKS PRIOR TO DEATH**

Your loved one may begin to appear restless, pulling at the bed linens or clothing. This is common and is due, in part, to the decrease in circulation to the brain and other changes in the body. Do not be alarmed or try to interfere or restrain such motions. Try to create a calming environment by speaking in a quiet, natural way; lightly massaging the hand or forehead; or playing soothing music. You can ask the members of your Tidewell team for other suggestions.

The person may also seem confused about time, place and the people around. It may help to identify yourself by name before you speak. Speak softly, clearly and truthfully when you need to say something important to comfort your loved one, such as “It’s time to take your medication so you won’t begin to hurt.”
Physical Changes

Urine decrease: The person’s urine output normally decreases and may become tea-colored at this time. This is referred to as concentrated urine and is caused by the decrease in fluid intake or decrease in kidney function.

Incontinence: Your loved one may begin to lose control of the bladder and/or bowels as the muscles in that area begin to relax. Protecting the bed and keeping your loved one clean, dry and comfortable are important, so discuss this with your Tidewell nurse.

Heart beat: You may notice changes in the person’s pulse, either increasing from a normal of 80 beats per minute to upwards of 150, or decreasing anywhere down to zero.

Body temperature can fluctuate between fever and cold.

Breathing pattern change: You may notice a change in your loved one’s breathing pattern. He or she may begin breathing irregularly with shallow breaths, or even experience periods of no breaths for 5 to 30 seconds, followed by a deep breath. The person may also have periods of rapid, shallow panting-type breathing. Sometimes there is a moaning like sound when the person breathes out. This is not a sign of distress, but rather the sound of air passing over relaxed vocal cords. These breathing patterns are common. Elevating the person’s head and/or turning onto the side may bring comfort. Hold your loved one’s hand lightly and speak gently and reassuringly.

Congestion: Your loved one may develop gurgling sounds coming from the chest, like a rattle. Sometimes these sounds become very loud and can be distressing to hear. If you watch your loved one closely you will notice that he or she is usually unaware at this point. It is probably harder for you to hear and watch than it is on the patient. Suctioning the secretions that are causing this sound is usually ineffective and can be hard on the patient. It may help to raise the head of the bed to keep the secretions pooling low and prevent gagging. Elevating the head and/or turning onto the side may bring comfort. Again, lightly hold your loved one’s hand and speak gently and reassuringly. Notify the Tidewell nurse if this begins.

Color changes: The person’s arms and legs may become cold, hot or discolored. There can be increased perspiration, often with clamminess. The underside of the body may become discolored as circulation decreases. This is normal. Irregular body temperatures can occur, so keep your loved one warm if he or she appears cold but do not use an electric blanket. If he or she continually removes covers, then just use a light sheet.
ONE TO TWO DAYS TO HOURS PRIOR TO DEATH

During this time, the nurse or hospice team may tell you the person is actively dying. Some people experience a surge of energy during this time. He or she may talk clearly and be alert when before there had been disorientation. The person may ask for a favorite meal when he or she has eaten nothing for days. Your loved one may sit in the living room with relatives and visit after not wanting to be with anyone for quite a while. This surge of energy is not always as noticeable as the above examples, but in hindsight, the change can usually be easily recognized. Embrace this opportunity to create a lasting positive memory.

Physical Changes

One to two weeks: The signs that were present earlier become more intense as death approaches.

Restlessness: Restless behavior can increase due to lack of oxygen or accumulation of waste products in the blood.

Breathing patterns: The rhythm of breathing becomes slower and more irregular. Breathing often stops for 10 to 15 or up to 45 seconds before resuming again.

Congestion: Respiratory noises related to congestion can become very loud. Positioning the patient on one side or the other may reduce the congestion.

Eyes: The eyes may be open or semi-open, but not seeing. There is a glassy look to them, often tearing.

Hands and feet: The extremities now become purplish. The knees, ankles and elbows, as well as the underside of the arms, legs, back and buttocks may become blotchy.

Responsiveness: Generally, a person becomes unresponsive (unable to respond to the environment) sometime prior to death.

AT THE TIME OF DEATH

At the time of death, breathing stops, as does the heart. You might feel like time stands still at that moment. Death is viewed by many as a reflective or sacred moment. It is a time to acknowledge that death can be filled with presence, connection, reflection, gratitude and love. Don’t despair if you are not present at the time of death. Death can be an intimate moment of reflection whether you are present or not.
There is no need to call 9-1-1 unless there is a decision to start resuscitation. Resuscitation is hard on a patient with advanced illness and the decision to resuscitate or not should be made in light of the wishes of your loved one. Tidewell will honor your wishes and be with you.

At the time of death, please call the Tidewell number. A Tidewell nurse will return your call and assist you through the process. The important thing to remember is that there is no need to be afraid.

You will have time and no need to panic. If other family members or friends are present, share stories, say goodbye or offer a comforting touch. You may wish to call family members who are not present for support or to allow them an opportunity to say goodbye. Talk with other loved ones, friends and family and plan your response.

A shift occurs in your life when the care of your loved one stops, but the love you have shared does not. Please take a moment — or several moments — to take it all in. Crying is a natural response and an honest means of expressing your feelings when words will not come. Others may find that they are unable to cry. This is also a natural response and the tears may come later. Allow yourself to just be who you are — there is no right way to feel or express your feelings. Allow those thoughts and feelings to be a celebration or reflection of the relationship you have with your loved one.

**SAFE MEDICATION DISPOSAL**

Tidewell must comply with federal, state and local regulations regarding medication disposal during hospice care. It is important for patients and families to understand the hospice procedure for safe medication use and proper medication disposal. Disposal of unused medications may be needed after a patient death or other circumstances in which the medications are no longer needed.

Proper medication disposal can reduce harm or risk associated with accidental ingestion, overdose or illegal abuse. The likelihood of harm is increased when drugs are not destroyed and remain in the home. Your Tidewell nurse will work with you to make sure you understand the options for safe medication disposal and may educate and assist as allowed in the policy and procedure. The nurse is required to record any medications disposed of or remaining in the residence after a patient death. A family member will be asked to witness this record. Tidewell staff is not allowed to transport medications in their vehicles for the purpose of disposal.
The Tidewell Hospice policy and procedure on Managing Safe Use and Disposal of Medication is provided below. Please review the policy as it offers specific information on safe and proper disposal of medications. At any time during hospice care you may contact a Tidewell nurse to discuss any questions or concerns regarding medication safe medication management and disposal.

Managing Safe Use and Disposal of Medications, Tidewell Policy 15.19
Effective Date: 2/17/2017

Purpose: The purpose of the policy is to describe how to manage safe use and disposal of medications during hospice admission.

Policy: Tidewell is committed to following best practice recommendations. Tidewell follows all applicable federal, state and local rules, regulations and guidance from Medicare and Medicaid programs. Tidewell’s intent is to protect patients, families and communities from harm, prevent illegal diversion of unused medications and reduce as much as possible the negative impact on the environment.

Procedure:

1. Upon admission to Tidewell in compliance with Medicare Hospice Conditions of Participation, a copy of Tidewell’s policy and procedure on Managing Safe Use and Disposal of Medications is given to and discussed with the patient, patient representative or family member.

2. Education on Tidewell’s Managing Safe Use and Disposal of Medications policy and procedure will occur on admission when medications are first ordered.

3. Documentation of the education will occur on admission in the patient chart.

4. Safe medication use is the responsibility of the patient and family/caregivers. Patients are instructed to store medication properly in a safe and secure location away from access of children, pets or unauthorized persons. Patients are instructed to never share medications with anyone else as medications are prescribed for legal use only by the patient. The patient and/or family/caregivers are responsible for the appropriate security of prescription medications.

5. Medication disposal may be necessary upon patient death, discharge, medication dosage changes, discontinuation or patient discharge if medications are no longer appropriate or necessary for patient care.

6. Medication lawfully prescribed and dispensed to the patient for the patient’s use and treatment are the patient’s property during the patient’s life. A family member may take possession of patient
property such as medications lawfully after a patient’s death expressly and only in order to dispose of the patient property or transfer them to a DEA Collector or law enforcement. It is not legal to transfer, share or sell medications with persons other than whom they were prescribed. The patient and/or family members are lawfully responsible and allowed to make decisions regarding the method of medication disposal.

7. A Tidewell nurse will be available to provide education and a demonstration on appropriate methods of medication disposal and to physically assist with medication disposal under the following circumstances:
   a. The assistance is requested by a patient or adult family member
   b. The patient is residing in a patient’s or adult family members home
   c. The patient or adult family is present physically for the duration of the disposal and documentation.

8. Documentation of Medication Disposal
   a. A Medication Destruction Record (Clin057) will be completed in all instances whether the nurse assists with the physical disposal or whether disposal is deferred or refused. The disposal is fully documented on the form and includes the patient name, date, named medications, strength, dosage form, quantity of medication, reason for disposal and disposal method. The form requires acknowledgement by a physical signature of the patient or adult family member and hospice nurse signifying the accuracy of the inventory and process.
   b. Tidewell staff in hospice houses in the case of DEA scheduled medications will also document the removal from inventory on form HH002 Hospice House Narcotic Record.
   c. A Medication Destruction Record (Clin057) documenting medication disposal will be forwarded by Tidewell staff to the Tidewell Compliance and Audit Department for inclusion in the patient chart.

9. Tidewell colleagues or representative staff will not transport under any circumstances medication for disposal on behalf of patient or family member. It is not lawful to do so.

10. Methods of Medication Disposal:
    a. **Household Trash** is one option for method for destruction of medications provided the necessary supplies are available on site to complete the medication disposal. Supplies may include sealable plastic bags, water, inedible substances such as coffee grounds, kitty litter, dirt or detergent.
    b. **Flushing** is an alternative option in selected situations for high risk medications. A list of medications recommended for disposal by flushing can be found on the FDA web site. The list
contains many narcotic medications used for treatment of pain. If non-flushing disposal options are not readily available or feasible, it is recommended that patient or family members consider allowing these medicines be flushed down the sink or toilet as soon as they are no longer needed to avoid accidental harmful or fatal ingestion.

c. Form Clin058, “Hospice Medication Destruction and Disposal Techniques”, provides additional instruction on physical medication destruction techniques and is found as an attachment to the policy.

d. Various **consumer commercial medication destruction products** may be utilized to dispose of medications. These products may be purchased through various vendors or pharmacies.

e. **DEA Take Back Events** can be attended for disposal. Patients and family members can visit the DEA’s website for more information about drug disposal, National Prescription Drug Take-Back Day events and to locate a DEA-authorized collector in their area.

f. A list of local **disposal drop off sites** allowing medication drop off by county is available as a reference through the hospice nurse or Tidewell patient portal.

11. In compliance with Assisted Living Facility and Long Term Care Facility rules and regulations, medication destruction for patients in those facilities will be according to the facility policy and procedure if one exists. If no procedure exists destruction will occur by the procedure above.

**References:**

1. Medicare Hospice Conditions of Participation. Subpart D: 418.106 Drugs and Biologicals, Medication Supplies and Durable Medical Equipment. Standards: Labeling, Disposing and Storing of Drugs and Biological.


HOSPICE MEDICATION DESTRUCTION AND DISPOSAL TECHNIQUES

Individuals should wear gloves during medication destruction to prevent unintended exposure through direct skin contact with liquids, gels and patches containing medication.

Household Trash Destruction Procedure

Medication destruction is accomplished by use of an alternative disposal container such as a sealable plastic bag, addition of water and inedible substances such as coffee grounds, kitty litter, dirt or detergent. Medications may be added sequentially in the following order to the disposal container.

1. Add solid drugs such tablets or capsules crushing them using a can or other heavy object as much as possible to enhance their ability to partially dissolve.
2. Add liquid drugs such as oral liquid drugs, rectal liquid drugs or liquid injectable drug vial contents.
3. Add gel drugs after opening the individual gel packets and squeezing out contents.
4. Add suppositories after removing outer wrapping.
5. Add patches by removing new patches from their packaging or used patches from the patient. Fold patches in half so that the adhesive/sticky side of the patches adheres to itself.
6. Add water to the disposal container to roughly double the volume in order to make slurry.
7. Add coffee grounds, kitty litter, dirt or other inedible substance to the slurry. Mix contents.
8. Close and seal the disposal container.
9. Place the disposal container in another opaque bag such as a grocery or trash bag and tie closed.
10. Throw sealed disposal container in regular trash (not recyclable trash).
11. Empty glass or plastic vials; drug wrappers or other drug packaging may be discarded in the regular or recyclable trash as appropriate.

12. Remove or mark through any personal identification information from prescription labels on containers and discard in regular or recyclable trash if appropriate.

**Flush Destruction Procedure**

The USFDA maintains a “should flush” drug list. *Any drugs appearing on this list are recommended to be destroyed quickly. If non-flushing options are not feasible these medications may be destroyed by flushing.* The FDA, Office of National Drug Control and DEA have determined that the risk of fatal exposure or unauthorized use of these “should flush” medications outweigh any potential negative environmental effects from flushing. Medication destruction is accomplished by use of toilet and sewer/septic system.

1. Medications may be added individually one at a time to the toilet bowl or one at a time to a single container and then by emptying the container contents simultaneously to the toilet bowl while flushing.

2. Add solid drugs such as tablets or capsules.

3. Add liquid drugs such as oral liquid drugs, rectal liquid drugs or liquid injectable drug vial contents.

4. Add patches drugs by removing new patches from their packaging or used patches from the patient. Fold patches in half so that the adhesive/sticky side of the patches adheres to itself.

5. Add gel form drugs after opening the individual gel packets and squeezing out contents.

6. Add suppositories after removing outer wrapping.

7. Flush medications down the toilet.

8. Empty glass or plastic vials; drug wrappers or other drug packaging may be discarded in the regular or recyclable trash as appropriate.

9. Remove or mark through any personal identification information from prescription labels on containers and discard in regular or recyclable trash if appropriate.