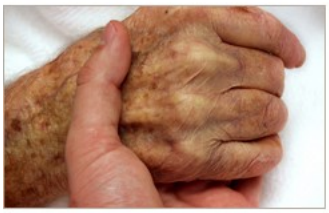

When Death is Near

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Overview

In the final phase of progressive life-limiting illness, patients and families face changes, challenges and choices that are unfamiliar and can seem overwhelming. This article offers information about what might be expected as death nears.

Please remember that when an expected death is thought to be within hours or days, the focus of care is usually on maintaining the person's comfort rather than pursuing tests and treatments. Also at this time, families may want to consider whether there are important cultural, spiritual or religious rituals that need to take place just prior to death or at the time of death. If so, it is helpful to inform those who will be participating and link with the health care team as required.

Some General Considerations

As a life-limiting illness progresses, some common concerns and considerations can arise. These include concerns about pain at end of life, difficult choices about care options, and the dilemma faced by loved ones who cannot be there.

A Common Concern: Will Pain Worsen As Death Nears?

Pain is one of the more common symptoms experienced by those living with serious illness. Understandably, it is common to be concerned that pain will steadily worsen and be poorly controlled as death nears. People may think: "If I have this pain now, and I'm not near dying, how bad will it be when I am closer to dying?"

What we see on television and in the movies has contributed to this perception. The reality is quite different, however.

While it is true that pain is a common symptom in advanced illness and merits the full attention and expertise of health care providers, it tends to behave consistently for a person throughout an illness. If pain difficulties have not been present, they are unlikely to develop near end-of-life. If pain has been present but manageable, it will most likely continue to be manageable rather than escalate out of control in the final days.

One study of patients with advanced cancer showed that in fact the prevalence of pain actually decreased from 52% about 6 weeks before death to 30% in the last week of life (Conill et al 1997). Perhaps this decrease in pain is because the dying process is one of shutting down, not escalation. Our energy decreases, our alertness decreases and we tend to rest and sleep more.

Of course, sometimes an individual's unique circumstances may result in increasing pain in the last weeks of life, however this would be unusual. In such situations, it is imperative that the health care team aggressively pursue comfort with all of the urgency and expertise possible.

See also: Pain

Difficult choices as death nears

As the changes described in this article develop in the final days or hours of a progressive terminal illness, difficult choices may arise. There may be questions about whether to provide food and fluids, receive blood transfusions, or treat infections. Ideally, the person who is ill makes the choices about treatments. When this is not possible, a family member or person chosen as substitute decision maker may be asked these choices. It can be very difficult to decide on tests or treatments for someone else, but usually there is some sense of what the person would say if they could. Consider asking "What would the person want done if he/she were able to tell us?" rather than "What do we want done for him/her?" This way the decision maker serves as the messenger for the patient's known values and beliefs, rather taking on the responsibility for care decisions.

It may feel to families as though these decisions could make the difference between life and death. Yet, it is important to remember that the underlying illness itself is not survivable - no decision can change that. These choices about health care options will not determine whether the person will live or die, but rather how the final days are experienced. The illness itself is bringing the approach of death, and health care decisions are focused on choosing the path that is most comfortable for the person who is dying, and that reflects the person's values.

See also: Health Care Decisions

When loved ones are unable to be there

Sometimes family members cannot be present as death nears, and they may feel guilty about this. It may help to remind them that their connection is meaningful through thought and spirit, and not physical proximity… whether they are just outside the room, in a different city, or a different country, the physical distance between them does not diminish the closeness that they feel.

It sometimes seems as if a person waited for a specific time to die. It may have been the arrival of a loved one, or the opposite… a time when no one was at the bedside. Families who diligently held vigil may be upset that the death occurred when they briefly stepped away. Although we cannot truly know whether people can wait for a moment of privacy and solitude to die, such a possible explanation may provide some comfort to those who were briefly away from the bedside at the time of death.

Sometimes family members arrive just a few minutes after death occurs – they may have been called to come in because changes were happening quickly and were not able to arrive in time. It is reasonable in such situations to sit down at the bedside, perhaps holding the hand of the person who died, and say whatever feels right.

Decreasing Energy With Illness

Although no two people experience illness in the same way, some generalizations can be made about how an illness begins to weaken the body when a person is nearing death. Over time, progressive health conditions deplete the body's overall energy and strength. Even if an illness mainly involves a specific organ or body system, there is an impact on how all of the vital systems of the body function.

Declining physical capabilities

Serious illness depletes our energy reserves and limits our ability to rebuild them. In the final few weeks of life in progressive serious illness, there is usually a notable decrease in energy and day-to-day functioning. A very significant change is when the person is no longer strong enough to be out of bed. When this is caused by overall weakness from the total burden of illness rather than by a specific, possibly fixable problem, it may signal that there are only days or a few weeks to live.

The decline may appear to "speed up", as weakness seems to lead to even further weakness. This is often most striking in the last few days of life, when people can change rather quickly from being fairly independent to sleeping all of the time.

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When the body's energy reserves are nearly gone, there are dramatic changes in how a person appears. People spend more time sleeping, and less time in activities. When the energy runs out, there seems to be a sudden, big change. The person has no energy to be awake, to communicate, or to take in food or fluids. This change usually signals the final hours or perhaps days of life.

Dramatic fluctuations in condition

A person's condition can fluctuate quite significantly from one day to the next, or even during the same day. They can seem to go from looking good to seeming as though they have only hours to live, or conversely from seeming very poor to looking surprisingly good. This can be perplexing and exhausting for family and friends, who do not know what to prepare themselves for. These dramatic fluctuations likely reflect how little energy reserve the person has… there is nothing to draw on when there are problems.

Difficulty recovering from treatment

Treatments such as surgery, chemotherapy, and radiation therapy can be thought of as making "withdrawals" from the energy reserves of a person. In advanced illness, the health care team cannot reliably tell how much reserve someone has left, and some treatments may make a withdrawal that exceeds the reserves. In such cases the person would become steadily weaker and would not recover from the treatment. This is one of the reasons that the health care team may be reluctant to continue with further tests or treatments, as it can be very difficult to predict if the person has the energy to tolerate them.

Decreased food and fluids

As illness progresses, there is a point at which the body is not able to use the nutrients in food, resulting in weight loss and fatigue. More time is spent resting, and in the final few days before death, the person is generally sleeping most of the time. The body's various systems gradually weaken and shut down. As death nears, there is little or no appetite for food, and people are not usually awake enough to swallow safely.

Understandably, family members often find it difficult to see their loved one not eating or drinking, and feel helpless at not being able to nurture them in the way that is most familiar to them… by providing food. However, we know that near the end of life the body cannot use nutrients in food, and people do not become stronger or live longer when more calories are provided. The focus should shift to "feeding for comfort", as long as it is safe to swallow. If there is no interest in food, then there is no benefit to the patient in forcing the issue… in fact, this may result in increased nausea or a bloated sensation. If requested by the patient and it is safe to do so, small amounts of favourite foods can be provided.

See also: Lack of Appetite and Loss of Weight

Just as food intake becomes difficult and potentially unsafe, intake of fluids also decreases. People nearing death become dehydrated, meaning their body has less water than it would when healthy… this is a normal part of the natural dying process. This is not the same thing as being thirsty, which relates more to the person's experience of dehydration. A dying person would have to be awake enough to experience a sense of thirst, and thirst is usually related to a sensation of dry mouth. This can be addressed by giving mouth care with a moist sponge or cloth, or commercially available moisturizing sprays. In a comfort-focused approach to care, fluids are not generally provided by medical means such as intravenously unless there are specific reasons (sometimes to help with confusion, or to diminish medication side effects).

See also: Dehydration

Difficulty taking medications

Trouble swallowing medications is an expected development in someone who is nearing death. Health care providers should prepare for this by identifying other ways of giving medications. These may include placing small volumes of liquid medicine under the tongue or as drops or spray through the nose; delivering medication under the skin through injections (subcutaneous); through the skin with topical patches; or, rectal suppositories.

If care is being provided at home, these alternative methods must be available before swallowing becomes a problem. Planning in advance avoids having to look for such medications when pharmacies may not be open, ensuring that there is no disruption in comfort medications.

Discussion with the health care team should also include a review of all medications, stopping non-essential ones when appropriate. In the final weeks of life, there is no role for medications aimed at reducing long-term health risks, such as those intended to reduce cholesterol. Medications to manage symptoms (such as pain, nausea, or confusion) should be continued.

See also: Help with Medications

How Much Time Is Left?

As an illness progresses, it's hard to predict how long someone will live because each person's situation is different. A common guideline relates to how quickly someone's condition is declining, often called the momentum of change.

Momentum of change

If someone's condition declines significantly from month to month, this may indicate that the person has months left to live; if such changes happen from one week to another, it may mean there are only weeks of life left; if significant changes happen from one day to another or from hour to hour, then there may be days or hours left.

Those who are spending a lot of time with someone in advanced stages of illness usually have a good sense of when things are changing, even when the changes are subtle. These are usually accurate instincts; the momentum of change is a general guideline only. It is important for patients and families to be aware that sometimes a complication develops, resulting in a more rapid decline than expected. With this in mind, it may be helpful to address goals or tasks that must be accomplished while the patient is still able to do them.

Confusion, agitation, "visions"

As death nears, the brain experiences the same burdens as the other systems of the body. With weakening function of organs such as the kidneys, the liver, and the lungs, there is also a decrease in alertness and perhaps some degree of confusion (called a "delirium").

People who are confused often also feel frightened and threatened by people and things around them. This is called being "paranoid." Perhaps this is how we are programmed for self-protection; if it is difficult to sort out the world due to confusion, it may be safest to consider everything a threat. It is not usually productive to try to contradict the statements of a paranoid, confused person; this may simply feed the feeling of being threatened. It is generally best to acknowledge the distress the person must be feeling, and to commit to try to sort things out.

Confusion is very disruptive to care, causing significant issues:

•It is very upsetting for family at the bedside to see and hear their loved one act very out of character and perhaps be hurtful to others. Children or grandchildren may be afraid to visit, and family may feel that they have lost the person already, since the change in personality is so significant.

•There may be concern about possible self-harm or harm to others if restlessness and agitation are quite bad

quite bad.

•The health care team will have difficulties administering medications and providing care such as bathing and repositioning.

•There is a risk that people will stop seeing the patient as a person worthy of respect, especially if they think the patient's behaviour is embarrassing or undignified.

Most patients would feel dismayed if they were aware of their behaviour in these circumstances. One approach to guiding care decisions about someone who is confused is to imagine that they could look in on themselves from the perspective of when they were well – how would they feel knowing their current circumstances? If they had a choice, most people would feel that such confusion and paranoid behaviour causes an unacceptable loss of dignity, and would prefer to be sedated.

What happens when people are confused?

Sometimes confused people will misinterpret things, such as thinking that a coat rack is a person, or a piece of clothing on the floor is a cat or dog. This is called an illusion. Other times, people will experience hallucinations, which is seeing, hearing, or feeling things when there is nothing there at all.

To the person experiencing them, these illusions and hallucinations seem very real, and may be frightening, comforting, or neither (they are just "there"). Sometimes people will see visions of relatives who have either died, or who are living but not actually present at that time. Do these experiences represent something spiritual or metaphysical, or are they simply the result of the brain being under a significant burden of illness? Obviously such a question cannot be definitively answered, however the following approach to such events may be helpful:

•If the experience is comforting for the person, then there is little to be served in either trying to treat it with medications or debate its true nature. Simply acknowledge how the experience must be comforting for the individual.

•If the experience is frightening and threatening for the person, it is important to provide support as much as possible. Consider medications to treat the illusions or hallucinations, and if possible look for treatable causes.

See also this article for more in delirium: Confusion

Use of sedation when death is near

When an expected death is within hours or a couple of days and the dying person is upset and confused, there will generally not be enough time to sort out possible causes or to reverse the confusion. The approach that can most effectively calm the situation is to administer medications that result in sedation, so that the person sleeps.

Once someone is sedated and calm in these situations, they will very likely remain sleeping until dying from their underlying illness. Reducing sedation in hopes of bringing back a state of alertness is not a realistic option when death is imminent. The body's systems are continuing to weaken, and the problems causing the confusion continuing to worsen. If the sedation is lightened then the distress will almost certainly return. The goal of care at this point is for the sedation to remain effective and the person to remain sleeping until the illness runs its natural course, with death occurring from the underlying progressive terminal illness.

Family members trying to decide whether sedation is appropriate may wonder whether the medication will bring about an earlier death. Families, friends, and the health care team should understand that when the underlying illness is expected to result in death within a few days to a week, or perhaps even one to two weeks, sedation with appropriate doses of medications does not influence the time of death. The goal of sedation is to use doses that maintain sleep but are not strong enough to hasten the natural dying process.

Being At The Bedside

What should I do at the bedside?

Friends and family may feel uncertain about what to do at the bedside. However, the simple presence of loved ones near the end is usually more important than what is done or said. Families often just go on visiting, reading, laughing and joking, telling stories, watching television…in other words, being a family and doing what they would normally do when together. This is quite likely what would most please the person who is dying – knowing that family members are there and supporting each other.

The health care team can also help those at the bedside take part in making sure the person is as comfortable as possible by providing some aspects of comfort care, such as moistening a dry mouth.

See also: Providing Care

See also: Caregiving Demonstrations

Conversations – Can they hear me?

It is not realistic to expect those who are near death to be able to participate in conversation. Family members may wish for a final, meaningful connection and regret not having that opportunity. However, even if the dying person is not conscious, family or friends who would like to say something should be encouraged to speak to the person, perhaps asking others to leave the room in order to allow some private time.

There is no way to know how much can be heard and processed by the brain when death is near, but we do know that hearing is quite a strong function. For example:

• When people are given an anesthetic for operations, as they drift into unconsciousness often the last thing they are aware of is the clatter and noise in the operating room.

• It is very unusual for people to lose their hearing from conditions that affect just the brain, such as a stroke or a localized tumour. The sense of hearing is well supported in different parts of the brain, making it quite resistant to such problems.

• We sometimes hear of people who have come out of a coma due to a temporary problem such as a head injury, who seem able to recall some things that were said while they were thought to be comatose.

Speaking to a dying person can be very meaningful, regardless of whether the dying person seems alert enough to respond. A final goodbye might be all that is wanted, and this should be encouraged.

Sometimes it seems as though the dying person needs permission to "let go"... to hear from loved ones that they will be able to carry on, and that it is okay to leave them.

If we assume that hearing or some level of awareness might remain intact in the unconscious dying person, then we should also be sensitive about the nature of bedside conversations. It may be best to speak outside of the room when discussing topics that might have upset the person when awake, such as frank discussions about how soon death is likely to come. Disagreements or conflicts are better dealt with away from the unconscious person's bedside as well.

Reflexes

When spending time at the bedside, family and friends might notice the development of a few specific reflexes in the patient, which might be concerning for them if they do not understand what is going on. People who are experiencing weakness in brain functioning – such as those near death from illness, or those who have had a stroke or other disease affecting the brain – may develop what are called "primitive reflexes." These are also seen in normal newborn infants. Families may notice these specific reflexes:

• Grasp reflex

When something is placed in the hand of the patient, there is a reflex to grasp the object, particularly when it is pulled away slowly. This can be troubling for visiting family and friends who have been holding the hand of their unconscious loved one, and find that as they try to leave, the grip becomes

holding the hand of their unconscious loved one, and find that as they try to leave, the grip becomes stronger. It seems as if the patient is giving the message "Don't leave me!" However it very well might be a reflex action that happens without a conscious effort by the person. It can be very difficult to leave the bedside if you feel that the person is trying to hold you there.

- **Sucking reflex**

When objects are placed in the mouth, there is a reflex to clamp the mouth shut, especially when attempts are made to withdraw the object. If this happens during mouth care with moist sponges or cloths, it can seem as if the patient is extremely thirsty, since there is such an effort to keep the object in the mouth. Caregivers might feel guilty at not being able to do more for managing thirst, however it is typically not thirst or hunger that drives this clamping of the mouth shut, but a reflex action.

The visitor dilemma

Social connectedness is important. People often express the connection by wanting to visit someone who is ill, and those who are dying often cherish the visits.

Yet someone who is dying has little capacity to entertain visitors and may become overwhelmed. Unless directed otherwise by the person who is ill, casual visits from acquaintances should usually be brief, and visitors asked to limit their visiting time. In some cases it may be best to have no casual visits at all. Neither the person dying nor the family should feel a social obligation to entertain or to meet people. Visitors can be politely thanked for their kindness and concern, and told it is not a good time to visit. If the setting is a health care facility, then the health care staff can take on that role, and spare family members the awkwardness of setting limits.

Final physical changes

There are some physical changes when a person is nearing death (minutes or hours), particularly in skin colour and breathing, that can indicate that the body is in the process of shutting down. These reflect the normal dying process, and cannot be prevented by medical treatments. Sometimes these changes can be concerning to those at the bedside, as we're not used to seeing them. In this final phase, the person will almost certainly not be conscious, and will not be aware. These normal changes are happening to the physical body of their loved one, and do not cause suffering.

The following sections discuss these changes, in the order in which they tend to appear.

Circulation and Skin

The circulation of the body gradually shuts down, which causes the hands and feet to feel cool, and a patchy purplish colour called "mottling" often appears on the skin of the extremities. The skin of the face may develop a bluish or purplish colour, related to decreasing levels of oxygen in the blood. The heart tends to beat more quickly, but not as strongly. This makes the pulse rapid and hard to feel at times. All of these changes are normal, and not distressing to the patient near end-of-life. Turning down the lighting in the room can make the colour changes less obvious.

Bowel and bladder function

As people are closer to dying, there will be less food or drink taken in and less production of stool, so bowel movements will be decreased. Managing constipation is not usually considered necessary in the final few days of life. Although incontinence of stool is not particularly common due to the decreased stool production, if necessary this can be managed with adult absorbent or incontinence products, waterproof pads and cleansing of the rectal area by care providers.

Urine production also decreases as the person takes in less fluid. In the last one or two days of life, there may be no urine output at all. Loss of control of urine is sometimes best managed with a catheter that is inserted into the urinary bladder and connected to a drainage bag. The presence of a catheter can help to prevent skin breakdown that might occur from wetness.

Breathing changes

Changes in breathing are generally the most significant physical signs that death might occur within minutes or hours. These breathing changes do not mean that the person is uncomfortable. When we are wondering if someone is comfortable with their breathing, we look at their facial expression and overall calmness, not their breathing rate or their oxygen levels.

We generally see changes in:

•how fast the breathing is – called the rate;

•how deep the breaths are – shallow, deep, or normal;

•how regular the breathing is – called the pattern;

•the kinds of muscles used in breathing;

•the mucous or secretions that can build up due to inability to cough, and perhaps the development of an infection.

While there is no specific sequence of changes seen, these are changes that commonly occur:

• Breathing rate and depth

As people become too weak to take strong, deep breaths, their breathing pattern typically adjusts by changing to rapid, shallow breaths.

•Breathing patterns

The breathing tends to take on a very regular, almost mechanical pattern, suggesting that the automatic centres in the brain have taken over control of breathing. It may be of normal depth at first. It then may become quite shallow, and more rapid.

There may be increasingly long pauses in breathing (apnea). This is usually an indication that the important breathing regulation centres of the brain are weakening, and may indicate that death is within minutes or hours. There may be regularly repeated clusters of fairly rapid breathing separated by pauses, or breathing may become very irregular overall. There may be variable pauses (sometimes up to a minute or more) between a few quick breaths that range from shallow to deep… this pattern is particularly likely to indicate that death may be near, even minutes or seconds away. When death occurs, the breathing simply does not restart after its last pause, and the heart stops shortly after, sometimes several minutes later.

•Muscles used in breathing

The muscles that are used in breathing may change so that muscles at the front of the neck are used. The shoulders may also lift up when the person is breathing in. This might seem as though the person is struggling. However if there is no sign of agitation or discomfort otherwise, this is simply the body automatically recruiting extra muscles to help in breathing to compensate for general weakness, rather than the person willfully struggling to breathe. If the person's face appears calm and peaceful it is likely that they are not distressed, even if they seem to be working hard to breathe.

•Noisy breathing

There may be a build up of secretions in the lungs, which can be noisy (rattling or gurgling) and sometimes upsetting for people at the bedside. This is sometimes referred to as the "death rattle", and is likely not distressing to the unconscious dying person. However, medications can be given by injections under the skin, and sometimes by a patch or a gel on the skin, which will help dry the secretions if there is a possibility of discomfort. Treating the secretions may also make it easier for people to comfortably visit.

•Reflexive breathing movements

There may be very slight motions of breathing happening irregularly for a few minutes after the final breath. These are reflex actions and are not signs of distress.

An unexpected rally

Sometimes when patients are near death, they may experience an improvement in alertness and interaction which defies explanation. Although temporary, this may give family an opportunity to share thoughts or important feelings with the patient, sometimes resulting in very meaningful connections in the final days.

Such unexpected and puzzling fluctuations in alertness can be exhausting for family members, who have been preparing themselves for losing their loved one. They may doubt the credibility health care professionals who have been indicating that death may be soon. Usually a specific cause for these brief rallies cannot be determined, and supporting the family in enjoying this time together is the most helpful approach.

What Causes Death To Occur?

In progressive terminal illness, the deterioration in the last few hours and days is usually a total body process. Even when the illness relates mainly to a specific organ or body system, it affects the entire body, and all of the important systems progressively weaken. Often in the last day or two people develop an infection in the lungs (pneumonia), since they are too weak to cough and clear the secretions that the lungs normally produce. This infection generally does not respond to antibiotics, due to overall frailty and a weakened immune system, and adequate oxygen levels cannot be maintained.

Death eventually occurs when the heart stops, because it cannot function when the other vital systems are shutting down. This is why efforts to restart someone's heart with cardiopulmonary resuscitation (CPR) rarely work in such situations… the heart can't be restarted when the reasons that it stopped remain unfixable.

How do I know when death has occurred?

Usually the most obvious sign that death has occurred is that the breathing has stopped, and there are not even any slight breathing motions. The muscles of the face will have relaxed, and there will be no movement anywhere. Sometimes shortly after death there are minor muscle twitches, however these go away in a few minutes.

The pulse in the neck that is sometimes visible will have stopped, and a pulse cannot be felt at the wrist or elsewhere. There will be no heartbeat.

Sometimes the eyelids do not close all of the way, but stay half-closed. This is often the natural resting position. The pupils (the black circle of the eyeball) become quite large and do not change in size in response to light.

The person's body will become cool to the touch, which may take a few hours.

Family and friends may wish to stay by the bedside after the person has died and say whatever words seem appropriate and meaningful to them. There is no harm in touching the person's body, and there should be no rush to move the person until everyone has had a chance to say their final good-byes.

See also: The Moments after a Death

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