**Final weeks and days: What to expect**

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As serious illness progresses or as the body weakens with age (which may include multiple diseases), changes are common. These changes can affect how a person's body functions, how they may communicate, think, and also, how they may behave. Knowing what to expect can help you plan and prepare as death nears. If you are remaining at home, the article Remaining at home: What to consider provides additional information.

See also: Remaining at home: What to consider

# How much time is left?

As serious illness progresses, it can be hard to predict how much time may be left. Everyone's situation is different, and in the final months and weeks, diseases may follow different paths. Healthcare providers can explain how an illness will progress and what to expect.

A common measure used in advanced cancer to predict how long a person may live, is the momentum of change. It refers to how quickly a person's health is declining. If the person's condition declines from month to month, this generally indicates that the person has months left to live. If changes happen from one week to another, it may mean there are only weeks left. The momentum of change is a general guideline only.

With some diseases, the future can be more difficult to predict, with periods of decline followed by periods of improvement and/or stability.

Regardless of the disease, sometimes complications develop resulting in a more rapid decline than expected. With this in mind, it may be helpful to consider goals or tasks that may be important to complete while it is still possible. These may be different for each person or family but can include things such as finalizing a will, having final conversations and saying good-bye.

# Expected Changes: Final months and weeks

### Decreasing energy

Overall energy and strength declines as a disease progresses. Over time, it is common to spend increased time in bed and to sleep for longer periods of the day. In the last few days of life, some people can change quickly from being reasonably independent, to sleeping all of the time.

### Food and fluids

It's normal for appetite and thirst to decrease. This can be difficult for family and friends who see providing food as an act of love and care. As serious illness progresses, there comes a point at which the body is not able to use and absorb the nutrients in food the way it used to, often resulting in weight loss and tiredness. Because the body cannot use nutrients in the way a healthy body can, forcing someone to eat or drink may result in nausea, a bloated sensation, or choking, as the muscles that help us to swallow safely also become weaker. People who find comfort in eating may choose to do so knowing they risk choking.

See also: Lack of Appetite and Loss of Weight and Dehydration

For more information about providing hands-on care, see Module 6 of the Caregiver Series on CaregiversCAN.

### Medication concerns

Trouble swallowing medications is common as serious illness progresses, as the muscles that help us swallow safely become weaker. Some medications and supplements become less helpful and can be stopped. For a number of medications, there are different ways they can be given if swallowing isn't possible. These may include:

- Liquid drops given under the tongue or the inside of the cheek
- Nasal sprays
- Through a special "butterfly" needle inserted under the skin (the needle is very small and is generally not felt if inserted properly)
- Patches applied to the skin
- Rectal suppositories

See also: Help with Medications

For more information about medications, see Module 5 of the Caregiver Series on CaregiversCAN.

## Changes in the final weeks and days

Regardless of the type of serious illness, the last days of life generally look very similar. If significant decline occurs from one day to the next, there may be days left. If changes are occurring from hour to hour, then there may be only hours left. It's important to remember that complications can result in a more rapid decline than expected.

Dramatic changes in the person who is seriously ill may cause concern for those who haven't seen them for some time. Preparing visitors for these changes by describing in advance what they can expect (e.g., they will be in their bed; they may doze off while you are talking to them; they won't be able to stand up to hug you, etc.) can be very helpful. This is particularly important for children. As death nears, the person who is seriously ill may be unconscious and unaware of the changes.

### Rapid changes in condition

A person's condition can change quite significantly from one day to the next, or even during the course of one day. Individuals can go from looking stable to seeming as though they have only hours to live, or from appearing very sick to looking surprisingly well.

### Circulation and skin

The flow of blood and oxygen throughout the body lessens as someone moves closer to dying, which can cause their hands and feet to feel cool or cold. A patchy, purplish colour can appear on the skin; this typically occurs on the hands, feet, and face. Not everyone experiences these changes in body temperature or appearance.

### Bowel and bladder function

As desire and need for food and drink decreases, less urine and stool are produced. Having a bowel movement every three days is a guide. Managing constipation may be less of a priority in the final few days. If urine isn't passing, this can be very uncomfortable. A healthcare provider may insert a catheter to ensure the bladder continues to empty, which can improve comfort.

### Breathing changes

Changes in breathing often signal that death may be close. Changes in breathing can look different for each person. For some, their breathing pattern quickens; for some, their breathing pattern slows down; for others, it can be a combination of the two. Pauses between the breaths can be short, very long (e.g., more than 45 seconds), and can change from short to very long and back again.

As people move closer to dying, their need and capacity to swallow lessens. A small bit of saliva can rest at the back of the throat, and when air moves across it as one breathes in and out, it can result in a wet or 'gurgly' sound. This may be hard to listen to but breathing rate, oxygen levels or the sound of someone's breathing do not indicate that the person is in distress. If the person's face and body is generally calm and relaxed, they aren't in distress. Sometimes medications can help to dry up some of the saliva. Turning the person (changing their position in the bed) may also help.

### Confusion and distress

As someone moves closer to dying, all parts of the body weaken, and that includes the brain. Alertness decreases over time. Confusion, while common, does not affect everyone.

Confusion can sometimes be a source of distress. The seriously ill person may feel frightened or even threatened by people and things around them, or they may act or say things that are out of character. It may be very upsetting for family and friends to see someone they care about experience confusion. Trying to correct the person often adds to their feelings of being threatened. Instead, reassuring them that they are not alone and that they are in a safe place, can often help. Healthcare providers have ways to treat confusion and distress.

Confusion may also, at times, be a source of comfort to the person who is ill. For example, in experiencing confusion, they may think they are in a place that is meaningful to them, or brings them comfort (e.g., a different city, a different home, etc.). f this occurs, going along with their experience of confusion can often be a supportive approach to take.

For more information about confusion, see: Confusion

### Visions

Sometimes people who are close to dying see visions of relatives who have either died or who aren't present. While this can at times be a source of distress to others, it is commonly a source of comfort for the person who is seriously ill. If the experience comforts the person, then there is little benefit to treating it with medications.

### An unexpected rally

Sometimes, someone who is close to dying becomes suddenly alert and interacts with those around them. While this 'rally' seldom lasts very long, it may provide an opportunity to share thoughts or important feelings. These random periods of alertness can be confusing to families and friends who may wonder if the person is suddenly getting better. These rallies are usually very short and are often followed by continued decline. Supporting each other is the most helpful approach.

See: How long have I got?

## Difficult choices

Difficult choices may arise as serious illness progresses. They might include:

- Whether to continue receiving food or fluids
- Whether to treat infections
- If transfer to a health facility is required

Ideally, the person who is ill makes these choices through an advance care plan or healthcare directive. If the person does not have an advance care plan and can no longer make decisions for themselves, or if they prefer that someone else makes these decisions, a family member or a substitute decision-maker chosen by the person, makes decisions on their behalf.

If you are making these decisions and aren’t sure what their choice would be, consider asking yourself, “What would the person want if they were able to tell me?” rather than “What do I want?” It may feel as though these decisions could be the difference between life and death. However, as the person cannot survive the illness, no decision will change that.

See also: Healthcare Decisions; ACP?

## Being at the bedside

Friends and family may feel uncertain about what to do and say at the bedside of the person who is dying. Being present is usually more important than what is done or said. Continue to visit and do what you normally do. Knowing that those they care about are there and supporting each other may comfort the person who is dying. Reading to the person, gently rubbing lotion into their hands, playing their favourite music, or placing warm blankets on the feet may be ways to provide comfort.

Some people may find this quiet time difficult as there might be little left to do for the person, often for the very first time. The feelings of grief and loss that often start at the time of diagnosis, may be felt more strongly.

See also: MyGrief.ca : Module 1 – Grieving before the loss

## Can the dying person hear me?

If the dying person is not conscious, those who would like to say something can still do so. While there is no way to know for sure how much the person can hear or understand, hearing is often the last sense to be affected by anaesthetic for surgery and people in comas often report hearing conversations and sounds. For these reasons, there is some thinking that the ability to hear remains even as someone moves closer to dying.

It is important to remember that even if the person is still conscious, having a normal ‘back and forth’ conversation may be too much to expect of them due to weakness/fatigue.

See also: What to say to someone who is dying; Tip for Visiting

## Not being at the bedside

Sometimes being present as death nears isn’t possible and some people choose not to be present. For those who wanted to be present but couldn’t, this can understandably be very difficult. It may offer some comfort to remember that feeling connected doesn’t necessarily require physical presence. Whether death occurs after just stepping outside of the room, or you’re in a different city or country, the physical distance between you and the person does not diminish your relationship and/or the closeness that may be felt.

Healthcare providers have commented that in some cases, family and friends have shared that the person was very independent and may have wanted to die alone. Some find this comforting.

## When death occurs

### What causes death to occur?

The decline in the last few hours and days usually affects the whole body, even if the illness is in a specific organ or part of the body. Organs start to shut down and the heart eventually stops because it cannot function without the other organs. Performing cardiopulmonary resuscitation (CPR) won’t help because the reason the heart stopped — the underlying serious illness — cannot be fixed.

## How should I react when the person dies?

Sometimes people worry about how they will react when the person dies. They fear that they might lose control or that they may not be strong enough to handle the situation. Remember, we are human, and when we are hurting, we express our pain in whatever way fits us as long as we do not harm ourselves or others. Society often places a high value on holding ourselves together and being 'strong'. However, expressing feelings is not a sign of weakness. Similarly, not showing emotion does not necessarily mean we don't have feelings. People who don't show emotion may be feeling overwhelmed or even stunned when the death happens. We do what we need to do, when and how we need to do it.

## After the person has died

After death occurs, you may want to take time to reflect, say a few words, touch or hug the person, or say some final goodbyes. Or you may prefer not to do any of these things, and that's okay too. It is important to try to provide time and space according to everyone's needs and cultural practices. Some may want to touch the person, and others may not. Some may cry loudly, and some may be silent. Some may need to leave the room, while others may need to spend time with the person who has died. Everyone has their own ways of expressing their grief. There is no right or wrong way to feel after someone has died, and it is common to feel a range of emotions (e.g., sadness, despair, relief, guilt, anger, worry, etc.).

## Grief and loss

Grief is a natural response to loss. Everyone grieves in their own way and in their own time. Often, we don't understand all of the ways grief can affect us and those around us. The Programs and Services feature can help you find grief support in your community. MyGrief.ca, a free online tool to support you in your grief and loss. MyGrief.ca can help you understand and approach the challenges you may be facing in your grief. It can help you to support others as well. It includes modules with content for specific losses including the death of a spouse, parent, child, loss due to dementia, MS, ALS, Huntington's and more.

KidsGrief.ca is a free online resource that helps parents, guardians, and educators to support children when someone in their life is seriously ill, is dying, or has died. It provides words, practical approaches, and helps build confidence to talk with and support children and teens in effective ways.

YouthGrief.ca is a free online resource, developed by and for grieving youth. It shares wisdom, experiences and advice from more than 30 young people who've been there, and know what it's like to grieve when someone you care about has died.

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