

What to *expect*



Advanced illness

Serious illness is difficult for everyone involved. It can be upsetting to watch changes in the health of someone who is important to you.

What happens to people who have an illness that will shorten their lives?

- They gradually become weaker.
- Their bodies lose the ability to use food to build muscle and strength.
- They often have a poor appetite and lose weight.
- They gradually lose their physical abilities and independence.
- They often rest and sleep more.
- They may find it harder to think, concentrate and remember things. Sometimes health care professionals can help with this.
- Even an illness that involves a specific part or system of the body affects the whole body.

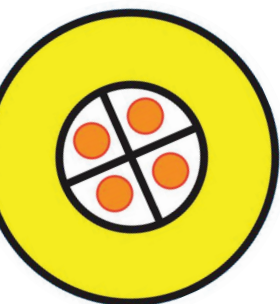
What you can do

- Listen to and respect the wishes of the person who is ill.
- Ask the person what is helpful and not helpful.
- Do not force someone who is ill to eat or drink.
- Report changes to health care providers.
- Ask questions and ask for help as needed.
- If the person experiences pain or other symptoms, advocate for good symptom management.
- Focus on quality of life, not quantity. Spend time doing what the person who is ill wishes to do.

“This was all new to me. I had never cared for anyone like that before... And one of the nurses from the health centre was awesome. If we had a question, she could answer it, showing us what to do...”

Katherine

Haida First Nation, British Columbia





CIRCLE OF LIFE
BY TRACEY ANTHONY

Final days

In the final days and weeks, signs that the body is shutting down tend to occur in this order:

- More time is spent in bed.
- More help is needed with personal care.
- The person interacts less.
- The person shows little hunger or thirst.
- Muscles, including those needed to swallow safely, become less able to do their job.
- The person may become confused, upset, and have 'visions' as the brain is less able to work properly.

In the last day or two

- The person is generally asleep.
- Hands and feet become cool. A patchy purplish 'mottling' appears, particularly on the hands, feet and knees.
- Little or no stool or urine is produced.
- Secretions may gather in the throat and lungs, causing a rattling or gurgling sound.
- As muscles get weaker, neck and shoulder muscles may be used to help with breathing. It may seem the person is struggling for breath, but this is not true.
- Changes in the breathing pattern are the clearest sign that the end of life is near.
- At first, breathing may seem almost 'mechanical'. Then it becomes irregular with long pauses.
- The person may rally briefly and unexpectedly.

How long will this take?

If the person's condition changes from week to week, the length of time remaining can be estimated in weeks. If change occurs from day to day, the person may live for a number of days. If the change happens from hour to hour, the person is likely to live for a number of hours.

Things to do

- Help the person transfer from bed to chair, walk a short distance or change position in bed.
- Ask the health team for help for the person's symptoms.

- Prepare for how medicine will be given if the person can no longer swallow. Medicine may need to be given as liquid under the tongue, by needle, or through a patch on the skin.
- Keep the person's mouth clean and moist with regular mouth care and moisture spray.
- Manage loss of bowel or bladder control with absorbent or incontinence products. Keep the person clean and dry.
- If necessary, a urinary catheter may be used to keep the skin from breaking down due to wetness.
- It is usually unnecessary to manage constipation in the final days of life.
- Help the person to change position, and keeping skin clean and moisturized can prevent skin breakdown and promote comfort.
- If lungs are congested, changing position may help. Ask the health team about medicine to help breathing.
- Be at the bedside. People who are very ill often sense the presence of others. They may still be able to hear even if they are not awake or responding.
- Reassure the person that you and others will be okay. Offer permission to 'let go'.

Helpful resource

www.VirtualHospice.ca/WhenDeathsNear

To see the Indigenous Voices video series and to learn more about living with serious illness and grief, go to LivingMyCulture.ca

Also available:

- What is palliative care?
- Compassionate caring
- Care at home and away
- Helping you feel better
- What to expect
- Honouring wishes
- Making memories
- Grief and letting go



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