

A Caregiver's Resource for Caring for your Loved One at Home during COVID

From symptom management to emotional care

Pain

- The goal is to keep someone alert, with the pain under control as much as possible.
- If pain is constant, give the medication on schedule even if there is no pain at the time, this helps keep the pain away.
- If your loved one has pain between the scheduled doses, give a breakthrough dose (if prescribed).
- Keeping a record of your loved one's pain and the scheduled and breakthrough doses will help the doctor adjust the dose.
- If more than 3 doses of breakthrough medication were needed in 24 hours, tell the doctor or home care nurse as the dose may need to be adjusted.
- Watch for side effects such as constipation, nausea, and any new confusion/agitation/drowsiness. Speak with the doctor or home care nurse if you notice them.

Confusion/Restlessness

- Tell the doctor or home care nurse if you notice the start of confusion and ask what can be done to reduce confusion.
- Remember that a person with a progressive illness may become confused due to the illness, infection, a side effect of medications, decreased fluids, or during the final days of life.
- Confusion may come and go and appear as increased sleepiness, agitation, being restless, lack of attention, hallucinations, strange thoughts, or as "pain all over".
- Maintain a calm, quiet presence and environment – keep loud conversations, radio, TV or other noise to a minimum.
- Use strategies that will help them stay orientated: a clock they can see, keep lights on during the day and off at night, gently remind them who you are and where they are, use a gentle touch to remind them of your presence.
- Explain any care or medications you are giving.
- Give medications for confusion as ordered by the doctor.

Shortness of Breath

- Keep a calm environment to help with the anxiety that comes with shortness of breath.
- If the shortness of breath is made worse with movement, walking, talking, dressing, etc., make sure you allow them frequent rest periods so they can recover their breath.
- Provide medications such as inhalers as ordered to help manage symptoms. If they are having difficulty using the inhaler, contact the doctor or home care nurse.
- A fan is not recommended since it may inadvertently spread droplets containing COVID.
- Oxygen can be helpful in some cases depending on the cause. Ask the doctor or home care nurse about this.
- Help the person into a position that makes breathing easier – usually sitting up and leaning forward over the edge of the bed or other high table with weight through the arms or elbows. Some people prefer to sleep in a reclining chair or with their head raised.
- Let the person rest and breathe as fast as they feel they need to in order to get their breath back.
- Opioid medications such as morphine or hydromorphone can be helpful for shortness of breath. The principles of use are the same as for pain with scheduled and breakthrough dosing. The home care nurse and/or doctor will give guidance on dosing.

Cough

- Like shortness of breath, cough can be managed with opioid medications such as hydromorphone or morphine.
- For a constant cough, scheduled and breakthrough dosing of an opioid is used. If the cough comes and goes, an 'as needed' medication may be all that is required. The home care nurse and/or doctor will give you guidance on the best medication and dose.
- Continue regular medications to help with breathing such as inhalers.

Secretions

- When a person is in their last hours or days of life, they may develop noisy secretion (mucus) in the back of their throat.
- Similar to snoring, the sound of the mucus is more distressing to those at the bedside than to the person themselves.
- It is caused by a small amount of mucus near the voice box in the throat. The person is usually deeply asleep and comfortable and not bothered by it. It may decrease when the person is turned.
- Occasionally medications can be given to help dry up mucus, but these medications can have side effects. Talk to the doctor.

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Final Hours and Days:

- When someone is in their last hours to days of life, they often sleep most of the time, have no interest in food or drink, have reduced or no urine output, have changes to their breathing pattern, and have changes to their skin temperature and colour.
- Continue to provide personal care and mouth care to keep their mouth moist. Continue to touch and speak to your loved one even if they no longer seem to be aware.
- For more information on the final hours and days, see “What to expect in the Final Days” – a paper copy can be obtained from your home care nurse, or visit: <https://myhealth.alberta.ca/palliative-care/resources/final-days>
- Your home care nurse can help provide information and support during this time.

Coping Skills:

- Set realistic goals for yourself for the amount of care you can provide.
- Try to set aside special time for other loved ones in your life; schedule it into your day.
- Break big problems down to a manageable size by working at them one step at a time.
- Take a break when you need it, and do not feel guilty.

Emotional Tips:

- Find ways to blow off steam. Try some vigorous exercise, pound a pillow, or sit alone in a car and scream - anything that works to relieve the tension.
- Have a good cry. It is a normal reaction and a good way of coping.
- Get resentment off your chest. If you need a sounding board, talk to a friend, family member, or professional.
- Step away from the situation if you feel your frustration rising, before you say something that you might regret in the heat of the moment.
- Practice deep breathing and relaxation techniques.
- Laugh without feeling guilty. It is a good way of releasing tension and reducing stress.
- Write your experiences in a journal as a way of releasing your emotions.
- Pat yourself on the back for all that you have done.

Communication:

- Your loved one may be experiencing many emotions such as fear, anxiety and anger. You can be a great support by being an active and interested listener.
- Be a sounding board for the person to talk about fears and concerns. Talk about your feelings and fears too.
- Accept what the person is saying, however different it may be from what you think.
- Talk about your concerns and encourage others in the family to do the same. Many people who want to talk about their fears are reluctant because they do not want to upset the family. On the other hand, respect the fact that the person may not wish to talk about some feelings and thoughts.
- Reminisce as a family to review your lives together. Remember the best and worst moments, family strengths, important times and events. Consider a legacy project, e.g., audiotape, cook/scrapbook, photo album.
- Continue to enjoy things together that have meaning such as music, art, sports, movies or books on tape.
- Help the person to stay in contact with friends and outside activities by assisting with letter writing, emails, phone calls, and virtual visits when in-person visits are not possible.

Helpful Resources

- My Health Alberta: Symptom Management
<https://myhealth.alberta.ca/palliative-care/resources/symptom-management>
- My Health Alberta: What to expect in the Final Days
<https://myhealth.alberta.ca/palliative-care/resources/final-days>
- Canadian Virtual Hospice: provides information and support on palliative and end of life care, and on loss and grief for patients, families, and professionals.
http://virtualhospice.ca/en_US/Main+Site+Navigation/Home.aspx
- A Caregiver’s Guide – A Handbook About End-Of-Life Care
https://www.stlazarus.ca/docs/publications/caregivers_guide_2015_en.pdf