

Tips for Family and Friends

Before a care decision is made:

- Consider your relative or friend's end of life values and preferences
- Stay informed and ask questions
- Encourage your relative or friend to be as independent and participate in as many decisions as he or she is able

With a health care provider, explore and discuss options:

- To help with shortness of breath and coughing (e.g. opioids, oxygen therapy, breathing techniques)
- To prevent infections (e.g. hand washing, flu and pneumonia shots, avoid touching face)
- For diet (e.g. dealing with low appetite)
- For dealing with fatigue (e.g. promote physical activity)

Your health is important too. If you are feeling overwhelmed, seek support from the Family Councils of Ontario.

www.fco.ngo

Phone: (416) 487-4355

Toll-Free: 1-888-283-8806

What Should I Ask About?

- What are my or my relative or friend's biggest fears about his/her health?
- How can I help maintain my or my relative or friend's quality of life?
- What symptoms do I, my relative or my friend have that are related to ALD?
- What are the options if I develop or my relative or friend develops heart failure as a result of ALD?
- What should I expect when I am or my relative or friend is dying?

Online Resources

1) Lung Association:

<http://www.lung.ca/lung-health/lung-disease/chronic-obstructive-pulmonary-disease-copd/resources>

- Symptoms and signs of flare-ups
- Breathlessness and oxygen therapy
- Fatigue and exercise

2) COPD Foundation: symptoms, medications, oxygen, and webinars

www.copdfoundation.org

The Palliative Approach for Advanced Lung Disease in Long Term Care

Version 2

A Resource for Residents, Family and Friends



What is a Palliative Approach?

This pamphlet was made to help persons with **Advanced Lung Disease (ALD)** (also called COPD) and their families know what to expect at the end of life so they can plan ahead. Talking about preferences early on is an important first step to a **Palliative Approach to Care**.

A Palliative Approach:

- Is for residents in long term care (LTC) with conditions that have no cure
- Shifts focus from prolonging life to maintaining quality of life
- Is an active approach that can start at **any stage of chronic illness**
- Is part of usual care
- Does not require a referral

A Palliative Approach includes:

- Treatment of curable conditions
- Pain and symptom management
- Social and spiritual support

For more information, please visit:

www.virtualhospice.ca

www.advancecareplanning.ca

What is ALD?

ALD is a **chronic progressive life-limiting illness**. This means that symptoms worsen over time and may affect how long one lives. ALD:

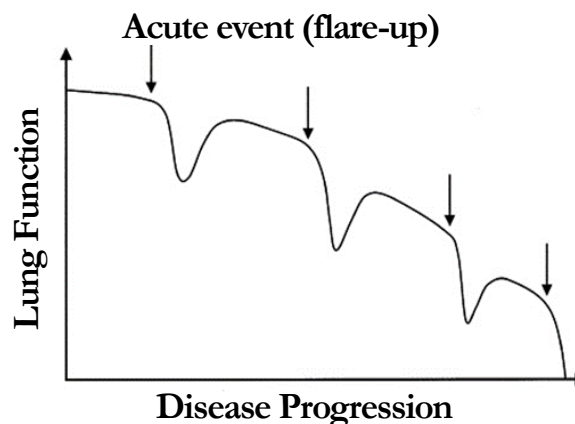
- Occurs when damaged lungs are not exchanging oxygen and carbon dioxide as well as they should
- Is a group of chronic lung illnesses (e.g. emphysema, chronic bronchitis, bronchiectasis, and asthma)

Residents with ALD:

- Will have bad days (more symptoms) and good days (less symptoms)
- Can live for months or years

How does ALD progress?

It is difficult to predict how long someone with ALD may live, so it is good to **hope for the best and plan for the worst**.



Living with ALD



The progression of ALD cannot be reversed and there is no cure. Being well-informed will help you to make care decisions if you are able.

Talk to your or your relative or friend's health care provider if you notice:

- More shortness of breath with little activity or at rest
- More weakness or tiredness (fatigue)
- Cough and wheezes with more sputum
- Decreased activity level (stays in bed or chair)
- Low appetite and weight loss
- Swelling in feet and ankles (edema)
- More hospital visits or respiratory tract infections
- More problems with cognitive function