# Tips for Family and Friends

What Should I Ask About?

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:

- For drugs to help with shortness of breath and fluid retention
- Before you give your relative or friend any over the counter drugs (e.g. Advil) or natural health products
- For diet (e.g. low salt intake or 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 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 HF?
- What are the options when I am or my relative or friend is no longer responding to the HF medications?
- What should I expect when I am or my relative or friend is dying?

#### **Online Resources**

- 1) **Heart Failure Matters:** interactive website that explains HF

  <u>www.heartfailurematters.org</u>
- 2) **BC Heart Failure Network:**documents for HF self-care

  www.heartfailure.ca/for-patients-andfamilies/co-management-resources
- 3) American Heart Failure Society: 10 modules (medications, end of life)

  www.heartfailure.ca/for-patients-and-families/co-management-resources

# The Palliative Approach for Advanced Heart Failure in Long Term Care

Version 3

# A Resource for Residents, Family and Friends







# What is a Palliative Approach?

#### What is HF?

## Living with HF

This pamphlet was made to help persons with **Heart Failure (HF)** 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**.

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

- Occurs when the heart is not pumping as strongly as it should
- Causes fluid to back up from blood vessels into the lungs and legs

### 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

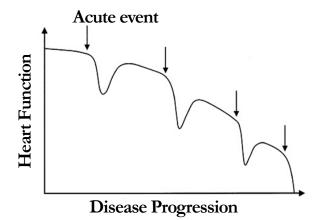
www.advancecareplanning.ca

#### Residents with HF:

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

# How does HF progress?

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





The progression of HF 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 weakness or tiredness (fatigue)
- More shortness of breath with little activity or at rest
- Weight gain (fluid retention) or weight loss (nausea or loss of appetite)
- More swelling in lower legs (edema) or in abdomen (ascites)
- Coughing (with or without sputum) that may worsen when lying down
- Rapid or irregular heart rate at rest
- More problems with cognitive function