

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:

- For drugs (e.g. allergy pills) or creams (e.g. calamine lotion or Uremol) to help with itchiness
- For clothing to help reduce itching (e.g. cotton)
- For diet (e.g. low protein and salt, ways to deal with low appetite/thirst)
- 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 AKD?
- What are the options when I am or my relative or friend's kidney function is too low to respond to medication?
- What should I expect when I am or my relative or friend is dying?

Online Resources

- 1) **National Kidney Foundation** (US):
https://www.kidney.org/atoz/atozTopic_Brochures
- 2) **Ontario Renal Network:** Dialysis and other Ontario CKD services.
http://www.renalnetwork.on.ca/info_for_patients/#.VjaYSa6rTVo
- 3) **Renal Resource Centre** (Australia)
<http://www.renalresource.com/pdf/IntroCCACKD.pdf>
- 4) **Kidney Foundation of Canada:**
<http://www.kidney.ca/brochures>

The Palliative Approach for Advanced Kidney 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 Kidney Disease (AKD)** (also called CKD) 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 AKD?

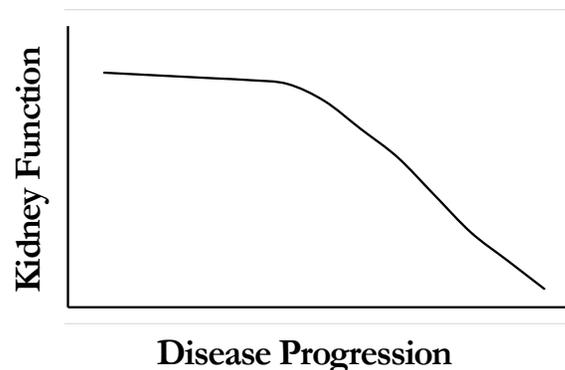
AKD is a **chronic progressive life-limiting illness**. This means that symptoms worsen over time and may affect how long one lives. AKD:

- Is also called end-stage renal failure
- Is mostly caused by hypertension (high blood pressure) or diabetes
- Occurs when the kidneys are no longer able to filter blood (kidney function is less than 15%)
- Causes wastes to build up in the body

Residents with AKD can live without symptoms for months or years.

How does AKD progress?

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



Living with AKD



The progression of AKD 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:

- Dry and itchy skin
- Confusion and sleep problems
- Lack of energy and tiredness (fatigue)
- Metallic taste in mouth
- Low appetite or weight loss
- Nausea and vomiting
- Shortness of breath
- Swelling of ankles (edema)
- Paleness or coldness (low iron)