DECISION SUPPORT FOR ADULTS LIVING WITH CHRONIC KIDNEY DISEASE

Chronic Kidney Disease (CKD) happens when the kidneys are damaged and do not heal. This affects how the kidneys remove wastes and water. Some causes of CKD are diabetes, vascular (blood vessel) disease and inflammation of the kidneys. In addition to affecting your kidneys, CKD can also affect other parts of your body, such as your lungs and heart. CKD has five stages but, with treatment and life-style changes, it may be possible to slow down or stop CKD from progressing from one stage to the next.

Having CKD can be a life changing experience. You and your family may feel uncertain about how to keep an eye on your health, manage your symptoms or choose the best treatment for you. It is important for you to share your thoughts and ideas with your health care team. They need to understand your preferences, personal situation and what is most important to you. Then you can work with your team to set priorities and determine the type of care that best fits with your and your family’s choices.

YOU WILL FACE MANY HEALTH AND LIFESTYLE DECISIONS WHEN YOU LIVE WITH CKD. MOST PEOPLE, WHO ARE LIVING WITH CKD, NEED TO MAKE DECISIONS ABOUT:

- Diet, weight and exercise;
- Medication;
- Lifestyle changes; and
- Planning for future care.

IF YOUR CKD PROGRESSES THROUGH ALL THE STAGES OF KIDNEY DISEASE, YOU MAY ALSO FACE TREATMENT DECISIONS ABOUT WHETHER OR NOT TO HAVE:

- **A Kidney Transplant**: a working kidney from another person is put into your body during an operation. This kidney will remove wastes and water.
- **Peritoneal Dialysis**: a catheter is placed in your abdomen during an operation. You use this catheter to put a special fluid into your abdomen to remove wastes and water. You do this treatment at home every night or four times per day.
- **Hemodialysis**: access to your blood is created during an operation using your own blood vessels (a fistula), an artificial blood vessel (graft) or a catheter. The fistula or catheter are attached to a machine that filters wastes and water out of your blood. You do this treatment three to six times a week at a hemodialysis centre with the help of a nurse or you can learn how to do this at home.
- **A Trial of Dialysis**: you agree to peritoneal dialysis or hemodialysis for a set number of treatments and then decide about doing dialysis as a long-term treatment.
• **Conservative/Palliative Treatment:** you decide not to have life supporting peritoneal dialysis or hemodialysis. You choose to receive medications and other treatments for physical and emotional symptoms.

For some decisions, it is quite easy for you and your healthcare team to reach a decision. For example, it is usually quite straightforward to make a decision about taking medication to control high blood pressure, because scientific evidence clearly shows benefits far outweigh side effects or long term complications. However, for many CKD care decisions, there is no clear ‘right’ or ‘wrong’ choice. In these cases you may feel uncertain about which option to choose or what next steps to take. You can help reduce your uncertainty by:

- getting information about your options,
- getting information about the potential good and bad aspects linked to each option,
- being clear about which of the good or bad aspects are most important to you, and
- getting enough support from your family and friends to work through your decision.

It is important for you to know and understand the best choices for YOU! Do not hesitate to **let your healthcare team know if you are experiencing difficulty in making a decision.** The goal is to make sure that, for any decisions you are facing, you receive information that is:

- **balanced** - both the good and bad aspects of the options are explained,
- **neutral** – not influenced by the personal opinions of healthcare members,
- **free of pressure** – you decide on the option that best meets your needs, values and preferences.

Your healthcare team will help you be involved in making decisions about your care and treatment by ensuring you:

- receive information that is **clear** to you,
- **understand both the good and bad aspects of the options you are considering**
- feel that your decisions are **consistent with your values and preferences**
- feel that you have enough support and advice to make an informed decision

There are many other resources available to you, such as: The Kidney Foundation of Canada (KFoC): [www.kidney.ca](http://www.kidney.ca). Also, the Ottawa Health Decision Centre (OHDeC) has developed some practical tools and resources to help patients and families facing tough decisions ([www.decisionaid.ohri.ca/index.html.](http://www.decisionaid.ohri.ca/index.html.))

**Be part of making decisions that are right for you!**

*Ask your nurse and healthcare team for help and support to make informed decisions that are consistent with your values and preferences!*

Reference: