# Self-Management

The World Health Organization defines '"adherence" as the extent to which a person's behavior in taking medications, following a diet, and/or executing lifestyle changes corresponds with agreed upon recommendations from a healthcare provider. So, how adherent are you? Do you follow your renal diet, take your medications as prescribed, go to every treatment and stay on for the full time?

People with kidney disease *can* live long and live well. Your day-to-day decisions have a tremendous impact on your health. Because of this, you must be an active and informed participant in the healthcare process. You see your healthcare team approximately 12 hours per week. In total, that is just half of a day. The rest of the time you are on your own. The process of dialysis can only do so much to improve your health. On a day-to-day basis, you are in charge of your own health, and the decisions you make have a huge impact on your outcomes and quality of life.

There are four important lessons you need to learn as a person living with chronic renal disease:

**1. Your illness is serious.** There are still patients out there who believe they have the "not-so-serious kind of kidney disease." If you don't believe it is serious, you will never make changes to improve your health, which will lead to more serious health problems.

**2. Your condition is essentially self-managed.** Every decision you make throughout the day, from what you eat to whether you walk or ride the bus, has an influence on your health. *You* are the most important individual in managing your illnesses.

**3. You have options.** There is rarely one perfect way to treat a condition. In the case of kidney failure, for example, patients can be treated through different types of dialysis. Each type requires a different degree of involvement from the patient and length of time and frequency on the machine. Transplantation is also a treatment option. You need to understand the different treatment options available and look at the personal costs and benefits of each. Only you can decide if the benefits are greater than the costs.

**4. You *can* change your behavior.** Rarely do patients leave the doctor's office and immediately enact whatever change was recommended. The reality is that it often has to be enacted in a series of steps. Significant behavioral changes can be made by setting small goals, taking that first step, and figuring out what you learn about yourself along the way.

# Tips

- **You need to know** all you can about your disease. Education is perhaps as important to your health as getting your prescriptions filled. Adult learning is often "self-directed." What we learn best is usually that about which we are most interested or motivated to know more. What do you want to know? What do you want to change or see differently? What are your healthcare priorities? What are your healthcare concerns?
- **Use your healthcare team** as experts for information, tools, and resources, including treatment options and consequences for not following recommendations. Then consider how these fit with your preferences for your desired state of health and outcomes.
- **You should feel comfortable negotiating** with your healthcare team about your health plan of care. Each patient is the expert in his or her own life. The federal regulations require dialysis facilities to invite patients to participate in their care plan meetings. *You should not just sign off on these papers without having been involved in the decision process.* Ask your healthcare team when they will be scheduling your care plan session. Or, ask to schedule one in the next month.
- **Dare to self-care!** Anyone can do dialysis with proper training, even you. No one will take better care of you than you. Unless you enjoy the time you spend in the dialysis center and the people you spend it with, consider doing home dialysis. People have better outcomes with home dialysis. If that is not an option for you, take more control of the care you get in-center. Talk to your facility about learning to take your own temperature, weight, and blood pressures. Clean your own access site. Learn to assess your access site. You can learn to pull your own needles, hold your site, and apply your own bandage. You can also learn to place your own needles (self-cannulation)! Yes, you can! Your center should be willing to help you participate more in your care. If they are not, you should ask why.

# Resources

**American Association of Kidney Patients (AAKP)**

1-800-749-2257
www.aakp.org

- *AAKP HealthLine*- **FREE**, 1-hour conference calls for patients and their families
- *AAKP My Health*- a **FREE,** safe, and secure tool to track your healthcare information
- *AAKP Library*- information about specific conditions, medicine, lifestyle, and news

**Home Dialysis Central**

www.homedialysis.org

- A 1-stop online source of up-to-date, unbiased information about all the types of home dialysis
- Detailed information about self-cannulation and the buttonhole technique

**Kidney School**

www.kidneyschool.org

- Learning modules provide a comprehensive online education program that allows patients to choose the topic about which they want to learn
- Available in audio format

**Mid-Atlantic Renal Coalition (Network 5)**

1.866.651.6272
www.esrdnet5.org

- Patient Education Series- topics developed by the Patient Advisory Committee
- Patient-focused website offerings