# You have a chronic illness...

# You have a lot of questions about how your life will change ...



Often when people are diagnosed with a chronic illness they feel a sense of loss and sadness. They don't know the answers to many questions. But help is available to address these feelings.

## **Working Through Feelings**

For many people, change is not easy. When newly diagnosed with a chronic illness, people often are forced to deal with necessary changes in lifestyle, lower energy levels, increased responsibility, threats to financial security and other concerns. These changes often cause feelings of sadness, grief, loss, or anger that can negatively affect the way people think and act and may lead to depression for some.

After speaking with kidney patients, we have learned that many do not seek treatment for these difficult and painful feelings due to fear of being seen in a negative light (stigma) and shame. It is important to know that while kidney disease affects everyone differently, many people have feelings of loss and sadness as they face the realities of a chronic illness such as kidney disease.

If you are experiencing overwhelming feelings, it's important to know you're not alone. Many react the same way to changes in their lives. It's important to remember that talking to professionals and getting support can help you move through these feelings and remind you that your feelings are normal and you are not alone!

## **A Process**

In 1969, a Swiss psychiatrist, Elizabeth Kubler-Ross, introduced a five-stage model that describes what people often experience (in part or in total) as they deal with grief or loss. The five stages of grief/loss are:

- Denial withdrawing, avoidance, forgetfulness, anxiety, difficulty focusing, missing treatments
- Anger irritability, easily frustrated, anger outbursts, short temper
- **Bargaining** feeling guilty, overthinking, feelings of "What-if"
- Depression feeling sad, withdrawing from family and friends, lack of motivation, decreased energy, hopelessness, sleep disturbances, anxiety
- Acceptance hopeful, coping, and learning to adapt

#### Chronic Illness (continued)

You may experience one, all, or none of these feelings when you are dealing with a change in your health. It's important to keep in mind that whatever you are feeling, it will not last forever. Working through these stages happens differently with everyone, and many people benefit from the help and support of others.

# What should you do if you are having these feelings?

If you don't address them, these feelings may continue to worsen and can have a negative impact on you both mentally and physically. This in turn can have a negative affect on your health and wellbeing.

- Talk to someone you trust who can help. This person might be:
  - Your dialysis social worker, doctor, or a member of the health care team.
  - A therapist you are able to locate through your health insurance or other resources.
  - Your primary care doctors.
  - Your family and friends.
- Take care of yourself as much as possible.
  - Make sure you are getting enough sleep.
  - Follow your diet and try to get some exercise.
  - Call 988 the national suicide prevention line, if you are having thoughts of harming yourself.

## What are the benefits of seeking help?

- It can improve your quality of life.
- It will help your mental and physical health.
- It can improve your ability to deal with change and other stresses.
- It may help you to feel less isolated.
- It can give you skills to help reduce stress and work through problems.

#### Important to remember!

You are the person you were prior to being diagnosed with kidney disease. You will be the same person while on dialysis. And you now have a team to help you when needed! Don't be afraid or ashamed to speak up – you are your best advocate!! Talk to your healthcare provider and discuss what type of treatment you both feel would be best for you.

"Self-care is how you take your power back."

— Lalah Delia





End-Stage Renal Disease Network Program

# To file a grievance, please contact us: IPRO End-Stage Renal Disease Network Program Corporate Office: 1979 Marcus Avenue, Lake Success, NY 11042-1072 • Patient Services: (516) 231-9767 • Toll-Free: (800) 238-3773 • Email: esrdnetworkprogram@ipro.org • Web: esrd.ipro.org

This material was prepared by the IPRO ESRD Network Program, comprising the ESRD Networks of New York, New England, the South Atlantic and the Ohio River Valley, under contract with the Centers for Medicare & Medicaid Services (CMS), an agency of the U.S. Department of Health and Human Services. Views expressed in this material do not necessarily reflect the official views or policy of CMS or HHS, and any reference to a specific product or entity herein does not constitute endorsement of that product or entity by CMS or HHS. Publication # ESRD.IPRO-G1-NW-20230428-200 v.6 8/28/2023 VB