Living Well with Dialysis: Getting the News

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It's the news nobody wants to receive. Learning that you need dialysis is never easy. For some people with renal disease, the diagnosis comes abruptly. Others have been living with renal disease for years, waiting for the other shoe to drop. Yet even for those who knew it was coming, it can be disorienting to find out the day has arrived.

The news is often met with a flurry of negative emotions. Fear, shock, anger, grief, anxiety, shame and self-blame are all common reactions. Your mind might be buzzing with worst-case scenarios. That's all normal. Fortunately, the reality isn't usually as bad as people fear. The adjustment takes time, but people can and do live well with dialysis.

One of the best ways to move toward acceptance is to arm yourself with knowledge. The unknown is always scary, so learn about your treatment options and what they entail. Regular appointments at dialysis clinics are no longer the only option for people with renal disease. Some people choose at-home dialysis, and others benefit from a method known as peritoneal ambulatory dialysis. Talk to your healthcare professionals to understand which options best fit your medical needs and lifestyle.

No matter which route you choose, you'll probably find that learning about what to expect helps ease your mind. Many nephrologists offer educational classes or have nurse
educators to meet with patients. Some match new patients to patient mentors who can help you understand what to expect. Support groups can also help you meet other people who are experiencing the same challenges you’re facing. In the beginning, it’s common to feel like you don’t fit in with other people receiving dialysis. Even though you’ve been told you need dialysis, your physical symptoms might not be that bad. You might feel younger or healthier than a lot of the patients you see at the dialysis clinic. When you start, it’s easy to feel like you don’t belong there. Sometimes, the feeling you don’t belong makes it hard to follow advice from healthcare professionals. It might seem like the information they share doesn’t really apply to you. But remember that people come to need dialysis for all sorts of reasons, and from all stages of life. Your situation may be more like others’ than you realize. Keep an open mind as you learn from your healthcare providers.

As you start to adjust to dialysis treatment, it’s common to experience a kind of “honeymoon period.” You might realize that the treatment isn’t as bad as you’d feared. You might start to feel better physically. That sense of relief is a welcome one -- but it can be a two-edged sword. After that initial relief, many patients become frustrated by the treatment regimen and the lifestyle changes that go along with it. That setback can be an unwelcome surprise.

So how should you deal with this difficult rollercoaster of emotions? Be kind to yourself. Remember, dialysis is unlike anything you’ve ever done before. Some days, you might feel like you’re coping better than you anticipated. Other days, you might feel like you’re not living up to your own expectations for yourself. Once again, these feelings are normal. There’s no one “right” way to adapt to your new routine. Take it day by day, and step by step.

Meanwhile, try to preserve as much of your pre-dialysis life as possible. It’s easy to give up on hobbies and activities if you feel overwhelmed, but you won’t know what you can handle until you try. In the long run, maintaining the activities you enjoy will make it easier to adjust to your new routine.

Experts also say that developing a support network is extremely valuable. Often, people with chronic diseases feel a sense of embarrassment. You might feel like you have a bright light shining on you, when all you really want to do is blend in. But others rarely judge us as harshly as we judge ourselves. So don’t be afraid to share your ups and downs with the people closest to you. Your friends and family members probably want to help you, if you’ll let them.

The early stages of adjusting to dialysis can be emotional and overwhelming. But with time and patience, many people reach a place of acceptance. By taking these steps to take control of your health, dialysis can help you live a rich and rewarding life.

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