

CHAPTER ONE

The Emotional Demands of Dialysis

This chapter will deal with some of the changes that we may face when we deal with dialysis. It will list some of the most common changes. It will provide some patient stories, so we can see how others have dealt with the emotions that resulted from those changes. It is important to remember that we are not alone. Even if we are on dialysis and dealing with anxiety or depression, we can still have loving and productive lives. There are no limits to what we can achieve with determination and the right tools. Many, many people have gone through the same things and we would like to share some of the things that helped us cope.

REACTIONS TO THE FIRST DIAGNOSIS OF KIDNEY FAILURE

Different people react in different ways. It is safe to say that nobody is happy when they hear that their kidneys are failing, or when they have just started dialysis. Most reactions are a combination of fear, uncertainty and sadness because of the changes in our lives.

FEAR

Fear is one of the most common reactions to loss of kidney function. We may be afraid of the medical system and of the medical process for treatment. We may be afraid of the unknown and of future losses in our lives. And we may be afraid of dying. Fear is most commonly expressed as either anger or depression.

LIFE CHANGES

Many of the changes that we are experiencing are obvious. Others are less obvious. But at some point, we must come to terms with them all.

- **Health Changes**

These are more obvious. Our kidneys are no longer working properly, and we must accept medical interventions to stay alive.

- **Family Dynamics**

These may be less obvious. Our “place” in the family may have changed. We may no longer be the primary source of income or the primary decision maker for our family. Or we may no longer be the one who takes care of everyone else. In fact, others may now have to take care of us.

- **Financial Changes**

Our income may now be reduced, and new bills are coming in. This can drastically change how we have been dealing with our money in the past.

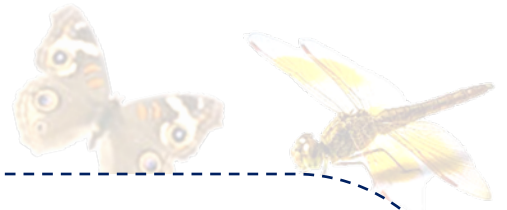
- **Loss Changes**

There may be a lot of losses associated with this change in our lives.

- ✓ Loss of energy – we may be dealing with about half of the energy we had before.
- ✓ Loss of our dreams and plans for our future – nobody grew up wanting to be a dialysis patient. A lot of plans for our future may be on hold or have changed entirely.
- ✓ Loss of control
 - Time – we are now dealing with dialysis schedules and doctor appointments. We have a lot less time for other things.
 - Bodily Functions – we can’t eat or drink like we always have. And we may have vomiting and evacuation issues.
- ✓ Sexuality – issues with performance or libido may need to be dealt with.
- ✓ Hobbies and Activities – a lot of things we have enjoyed in the past may no longer work for us. We may have to adjust or say good-bye to some of the things we loved doing.

All of this can sound very sad. And a lot of it is. But the truth of the matter is, many people have gone through all of this and developed very happy, satisfying lives. In fact, sometimes the new life may be better than the old life.

Patient Stories



Maria

I was standing behind a lady at the pharmacy and overheard the prescriptions that she was picking up. I knew immediately she was on dialysis because I was also there to pick up my prescriptions for the same reason.

I could hear her crying and as she turned to leave. I asked her if I could speak to her for a minute and she looked at me with tears in her eyes but said nothing. I quickly told her I was a dialysis patient and also a patient advocate. I could see the pain in her eyes.

Maria decided to sit and speak with me for a moment. She told me she was just put on dialysis and was depressed, scared and confused.

We spoke about her new life for about an hour. I suggested she speak to her nephrologist about her depression. I suggested she look into a local support group. She did both. After a month with the support group her depression was much improved and she never took medication for the depression.

