Patient Leadership Committee

Family Focus Series

I’m Not The Patient! So Why Do I Feel So Bad?
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We — the doctors, unit staff, billing office employees and the patients themselves — all expect a lot from the family of a patient. You also expect a lot from yourself and you do not cut yourself much slack when you feel that you have not performed up to expectation. You may be a husband or wife, son or daughter, best friend or maybe you are an ex-spouse who stepped back into the patient’s life when illness came to call. Whoever you are, you are the person who has stepped up to help the patient carry the burden of living with chronic kidney disease (CKD). You want your loved one to live well and that is exactly what the rest of us are counting on. Your involvement makes providing treatment and living with treatment easier.

But what are you doing to make sure you also live as well as possible? Numerous times I have heard family members say things like, “I need a medical procedure done but I just cannot take the time because my wife needs me” or “I could really use a vacation but who would take care of Dad?” No, you are not the patient but your life has probably changed almost as much as theirs.

Dialysis patients are very susceptible to depression so it should come as no surprise that the people closest to them would be more vulnerable as well. Let’s take a look at what depression is, at what you, the families, are dealing with and ways that you can take care of yourself.

According to the Diagnostic and Statistical Manual IV, depression is a mood disorder. Common symptoms of depression are: 1) depressed mood nearly every day, 2) lack of interest and/or pleasure in most activities, 3) changes in appetite/significant weight loss, 4) insomnia or excessive sleep, 5) psychomotor agitation or retardation, 6) fatigue or loss of energy, 7) feelings of worthlessness or inappropriate guilt, 8) lack of concentration and 9) recurrent thoughts of death (not just fear of dying). A major depressive episode might be diagnosed for someone who presents with five or more of these symptoms, including number one or two, during the same two-week period.

Other non-involved family members, friends and acquaintances might wonder why you would be at risk for depression when, as noted previously, you are not the one who is ill. If those people had any idea what you are coping with, they would not have to ask that question. You may have experienced any number of life changes, such as financial hardship (due to employment changes), role changes (children caring for parents), relationship problems (emotional distance/loss of intimacy) or just the large amount of time you spend transporting your family member to hemo or helping them with their PD treatments at home.
From an emotional standpoint, you may wrestle with the same feelings as your family member. You also experience fear due to loss and change and an uncertain future. You may also have periods of anger. Anger at the patient for “getting sick.” Anger at God for “allowing it to happen.” Anger at the rest of the world for going on with its normal routine while your world has been turned upside down.

You may also be suffering physically. You are tired all the time because you have to keep working, be a caregiver, raise children, run the home, just plain do EVERYTHING! You may also be more susceptible to illness because your physical reserves are so depleted. Or you may be putting off medical care for yourself until “a better time.”

You jeopardize your own health because you feel like you just do not have any other option.

Then there is the fact that everyone, including you, puts all the focus on the patient. The patient may be self-absorbed as he or she tries to cope. The dialysis staff is busy providing direct care services to the patient. Family and friends want to know how the patient is doing. Sometimes we all forget that helping you take care of yourself IS taking care of the patient.

So what can you do to take care of yourself considering the situation you are in?

1) Express your emotions to someone you feel comfortable with. Even the anger, fear, guilt and worry. There are no “bad” feelings, just feelings.

2) Take some time for yourself by asking other family members or friends to assist you with concrete duties. A retired friend might be able to transport the patient to hemo one day a week. One of your children could stay with grandma while you go for a doctor appointment. If someone in your life says, “let me know how I can help,” look them in the eye and tell them what you need. Too many times I have had people say to me “I just couldn’t ask my family or friends to help me.”

Well, why not? You may be doing such a good job acting like everything is fine that the rest of us may not realize, for a time, that you are struggling also. The people who care cannot read your mind and by the time we pick up on the clues you have probably already suffered far too much.

3) Reconnect with your place of worship. Perhaps you have not attended services for many years or maybe your recent attendance has become sporadic due to the illness of your family member. Regardless of the time that has passed, this can be an important source of hope, help and support. Even if you can no longer attend services, your church can still minister to you. Providing
spiritual care to shut-ins is a common practice at many churches. Also, it is not unusual for the people of a congregation to offer assistance, as well as emotional support.

4) Take time for your physical needs. Go to your doctor when you are sick or hurt. Do not ignore symptoms hoping they will magically “go away.” When you need a rest, make arrangements for someone to cover your responsibilities for a few hours, or if possible, for a few days.

5) Talk to the social worker at your dialysis unit. We are not just here for the patients. We realize that the well-being of the patient is tied to your well-being and vice versa. The social worker can be a source of support, counseling, information, referral, comfort, tissues, etc...

Social services vary from state-to-state, county-to-county, and even city-to-city. For this reason it is best to discuss your needs with the social worker. He or she will know, or can find out, about services available in your area. Most services are part of an umbrella of programs administered by agencies, such as the Area Agency on Aging, Department of Job and Family Services, Community Service Organizations, etc...

The majority of agencies are administering government funds and charitable contributions. Do not assume that you do not qualify for services. Programs have different guidelines and some have a sliding fee schedule for people who do not meet the qualifications for free services.

Services potentially available to assist patients and families (depending on where they live) include transportation, nursing/aide services, home delivered meals, personal emergency response systems, respite care and homemaker services. Some agencies provide adult daycare, chore services, counseling, support groups and friendly visitors. Depending on your situation, you might benefit from employment placement and counseling, energy bill credits, veterans services or prescription drug assistance programs.

Sharing your concerns and needs with the social worker will allow you to determine what assistance might be available from your community. However, please remember that “the government” is not going to meet all our needs. Families have the primary responsibility to take care of their own. Once you have established what your family, friends, church, etc., can assist you with, you can investigate how community services might fill in the gaps.

6) When necessary, medication and counseling can make a world of difference in how you feel and your ability to cope. You are important and you should not suffer needlessly. Depression is a treatable condition and that is why we want you to be aware of your risk and the things to look for.
But no matter where you are on the continuum of feeling and emotion, from occasional sadness to an actual depressive episode, there is help and hope. It is up to you to take that crucial first step and ask for help.